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ABSTRACT

This final report describes activities and accomplishments of the 3-year federally supported Minnesota Deaf-Blind Technical Assistance Project. The project provided training and technical assistance, information sharing, and support services to families of children with deaf-blindness. Activities and accomplishments included: collaboration with other projects, on-site technical assistance visits to schools and families, publication of a newsletter, facilitation of greater involvement of parents and families, formation of a Transition Resource Team to identify and address needs in the area of transition, identification of new children with deaf-blindness, efforts to define Free Appropriate Public Education standards for this population, development of a collaborative effort at the Minnesota state schools for the deaf and the blind, collaboration with similar projects in other states, participation in a conference for Usher Syndrome youth, provision of local inservice training for teachers, and implementation of an annual Summer Institute and an annual family weekend. Individual sections of the report describe the project's mission, goals and objectives, problems and resolutions, research and evaluation findings, and impact. Attachments to the Final Report include: two pamphlets; a copy of "The Deaf Blind Inquirer" (vol. 1, no. 1); a calendar of events; "Parent Pages" Manual; Needs Assessment for Parents of Children with Vision and Hearing Loss; Activity Sheets for Children Suffering from Deaf Blindness; and a Guide to Services for Individuals with Deaf-Blindness. (DB)

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ED 394 239

Minnesota Deaf-Blind Technical Assistance Project
Final Report: October 1, 1992-December 31, 1995
Project # H025A90027

By
Eric Kloos
Coordinator
Minnesota Deaf-Blind Technical Assistance Project

EC 304759

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II. Executive Summary

The three year grant cycle saw an increase in the number of children identified in Minnesota from 208 in 1992 to 258 in 1995. The Project also experienced annual turnover in staff, with the position of Director and Coordinator changing with every project year. By the end of the grant cycle, the changing staff had settled, and the strength and effectiveness of the team had increased greatly.

The Project Director, Dr. George Holt, has well developed relationships with the special education director's throughout the state that have been a great asset for the Project. The visibility and profile of the Project statewide has increased with the involvement of Dr. Holt.

The Project Coordinator, Eric Kloos, has provided continuity with the Project, starting the grant cycle as a Family Support Specialist and being promoted into the Coordinator position. He has developed multiple interagency collaboratives that have had a statewide impact.

In the third year, Sally Prouty, in collaboration with FIND, Inc. and the Children's Discovery Project, worked with the Project as the Family Specialist and lead point of contact to families in the state. Through this successful collaboration, new families were identified and consistent contact and support provided for families. The Parent Pages newsletter was also a source of information for families and service providers.

The School and Support Specialist, Jo Hausken, left the Project in August of 1995. In addition to doing on-site technical assistance visits to schools and families, Jo also completed the annual census, and planned meetings for the Transition Resource Team.

Dissemination of Project information has taken on many forms to keep pace with increasing technology. The Project newsletter received several facelifts. It went from a newsletter aimed mainly at educators, to focusing on families, to covering the entire community. The latest version, the DeafBlind Inquirer, is a compilation of information from around the DeafBlind community. It includes national, state, and local information while focusing on children, families, adults, education, rehabilitation, community events, personal interest stories, and multiple related services. The idea is to jointly produce and provide equal access to community wide information. In doing this, gaps and communication barriers are reduced and hopefully eliminated.

The changes in staff also had an impact on services and program that the Project offered. Parents assumed greater leadership throughout the grant cycle and took the lead in planning and chairing family weekends. Additionally, parents sought and received additional funding from the Hilton/Perkins Foundation to expand programs to include Saturday family workshops. The parents look toward the future in exploring distance technology to make family activities available to all parts of the state. The family weekend increased in number of families every year, hitting a high of 13 families in 1995.

Extensive needs in the area of transition were identified and addressed. The Transition Resource Team (TRT) was formed in 1994. After studying several models, the TRT formed, in connection with the state transition initiative. The TRT currently includes 32 people from families, schools, and agencies throughout the state.

Technical assistance around the state included an array of individual and school-based needs. The Project helped facilitate the formation of the Deaf-Blind Connection (DBC) at the Minnesota State Academy for the Deaf (MSAD) and the Minnesota State Academy for the Blind (MSAB). This collaborative effort is the first of its kind between state schools for the deaf or blind to develop services for their shared pupils. Formed with an emphasis on Usher syndrome students, the initiative has expanded to include an identified 10 percent of the children between the two academies.

Technical assistance requests also reached into new areas of the state. Although the state unduplicated child count increased only slightly over the three years, working through the Regional Low Incidence Facilitators (RLIF) identified new children in several regions of the state. The RLIF's are regional projects that coordinate services and training in the multiple low incidence areas within each of the eleven regions of the state.

In a statewide effort through the Department of Education, the project led an effort to define Free Appropriate Public Education standards for individuals with deaf-blindness. The effort included teachers, agencies, and parents in the development, and have been presented to the state Special Education Advisory Council for future steps toward implementation.

Multi-state collaboration with other states 307.11 projects also provided successes in two areas. The Great Plains Regional Alliance was formed with projects form Montana, Nebraska, North Dakota, South Dakota, and Wyoming. With support from TRACES, these states formed an alliance to address common issues in identification and service to American Indian populations on reservation lands.

Minnesota also participated in a conference for Usher Syndrome youth in New Jersey/ New York. Centered on common issues identified from these states on the intensive needs of this unique population, the interaction of states helped brainstorm on areas of common service. Minnesota looks to continue collaborative efforts with these states in the next grant cycle.

In addition to local in-services for teachers and the annual Summer Institute, the Project collaborated with the Perkins National Deaf-Blind Training Project to select and support three teachers from Minnesota to participate in a graduate level course in deaf-blind communication strategies at Michigan State University. The selected teachers were from geographically diverse parts of the state, and have increased local capacity through this collaboration.

V and VI. Purpose, Goals, and Objectives:

Mission: The Minnesota Deaf-Blind Technical Assistance Project is a team of dedicated individuals committed to supporting services to children and youth with deaf-blindness throughout the state. Our vision for service is demonstrated through training and technical assistance, information sharing, and support services for families.

Goal #1: To Develop and Disseminate Resources.

Objective #1: To publish the Advisory Council's Guide to Program Development.

Objective #2: To establish regional dissemination of the Advisory Council Document.

Objective #3: To publish a deaf-blind newsletter twice per year.

Objective #4: To expand dissemination of Project brochure to teachers and low incidence coordinators.

Objective #5: Continue to update and disseminate resource library materials list to educators, families, and service providers.

The Advisory Council document was completed in August of 1994, and dissemination has occurred since that time. Approximately 435 copies of the document have been disseminated, both statewide and nationally. The newsletter evolved over the life cycle of the grant. The original format, The Informative Link, was not friendly to readers, especially parents. In the second year, efforts focused more of families with the Parent Pages newsletter going out every other month. It was more practical, up-to-date information that was also useful to teachers and service providers, but focused on the parents. In the third year, Parent Pages continued, but the DeafBlind Inquirer was developed also. This interagency collaborative effort aimed to provide the DeafBlind community in Minnesota equal access to information across agency or age lines. It focuses on consumer issues, agency services, community updates, family issues, technology, education, medical, rehabilitation, national news, and perspectives from the DeafBlind community. The materials resource library continued to grow and usage increased over the grant cycle. We increased access by adding e-mail and a toll-free number to access the library. One hundred and twenty-four people visited the library over the grant cycle. 2400 brochures and 600 resource library materials lists were disseminated in library visits, mailings, and conference displays/presentations.

Goal #2: Provide Technical Assistance Throughout the State.

Objective #1: Provide on-site consultation to educators, service providers, and families.

Objective #2: Continue to conduct in-service training sessions for school personnel on a regional level.

Objective #3: To create and maintain a databank of individuals who have special knowledge or have special skills in working with deaf-blind individuals.

During the three year grant cycle, 63 on-site technical assistance visits were made by Project staff. These visits were spread out widely throughout the state, and 5 of the visits led to regional workshops. These training sessions were attended by 129 people, that included parents, extended family, teachers, agency staff, and group home staff. Work in these areas combined with working with Regional Low Incidence Facilitators helped identify areas of expertise within the various regions of the state.

Goal #3: Provide Educational Training on Current Issues for Individualized Program Development and Inclusion for Children and Youth With Deaf-Blindness.

Objective #1: To continue sponsoring the Summer Institute for Teachers.

Objective #2: Provide forums for information sharing at the practitioner level.

Objective #3: To provide directors of special education and coordinators of low incidence programs with direct information about identification, assessment, and program planning for individuals with deaf-blindness as well as the services available to individuals with deaf-blindness.

The 1993 and 1994 Summer Institutes were held at Bethel College in the month of August. In 1995 a slightly different approach was attempted, as the Summer Institute was held in late June at St. John's University, near the geographical center of the state. Attendance from Twin Cities based teachers was down, but attendance from areas of greater Minnesota increased. Attendance numbers were fairly constant each of the years, despite having different topics and themes. The Institutes averaged 40 people in attendance per year, mostly teachers with some parents, deaf-blind adults, and adult service providers also attending. Information sharing occurs in many places with the success of the interagency collaborative efforts that are in place. Practitioner input has also been sought regularly to supplement the deaf-blind education standards. Due to the ongoing efforts of the Project Director and Coordinator, relationships with the special education directors and Regional Low Incidence Facilitators have improved dramatically over the grant cycle. This has made dissemination of Project information and resources much more effective than the system three years prior.

Goal #4: Continuation and Expansion of Family Support.

Objective #1: Continue to hold annual family enrichment weekend.

Objective #2: To continue to expand the role of parents in the family support project so that they assume major administration of the family project activities by 1995.

Objective #3: Develop and implement a statewide family mentor program as part of the family support project to enhance the support network of families of children and youth with deaf-blindness.

The grant cycle saw growth and strengthening to the area of family support. The Children Linking Families Weekends were held once a year and attended by 36 families, and 340 people total, including families, volunteers, speakers, and interpreters. In year two, the Project started family workshops. Four were held and included Steve Perrault and Kathy McNulty working with the group to define mission, and future goals. In year three, we added a parent perspective to the Project with Sally Prouty. Through her consistent contact with families, through the Children's Discovery Project, more family contact was made than ever before. This contact also provided an ongoing access to the needs of parents and families. The Project also supported 6 families and 4 consumers to attend national conferences and disseminate the information within our state. These conferences included the American Association of the Deaf-Blind annual conference, Retinitis Pigmentosa Foundation Conference, CHARGE Syndrome conference, and an Intervenor training in Utah.

Goal #5: Expand Interagency Collaborative Planning and Development.

Objective #1: To support interagency planning in the area of CHARGE Syndrome identification and programming.

Objective #2: To continue to support and be involved in interagency collaborative planning and development through the Minnesota Coalition on Deaf-Blindness.

Objective #3: To collaborate with other state projects in the area of case management services.

Objective #4: Enhance the evaluation center at the Minnesota State Academy for the Deaf and the Minnesota State Academy for the Blind to include functional assessments for deaf-blindness.

Interagency collaboration continues to be a foundation for this Project. Many of the components have changed since the original grant was written, but have been replaced with more timely, effective interagency projects. The Minnesota Coalition on Deaf-Blindness disbanded shortly after this grant cycle started. In its absence, the Project's Advisory Council lead the way to facilitate interagency work on deaf-blind issues in the state. It is through this work that the community-wide newsletter and other ideas were formed and actualized. Collaboration with the Minnesota State Academy for Blind and Minnesota State Academy for the Deaf improved relations greatly over the grant cycle. Starting with functional assessment issues, the focus soon came back to how the academies could work together to meet the needs of their shared pupils. In 1995, the Deaf-Blind Connection, comprised of 30 staff from the two schools, was born. The team is focusing on the areas of training (staff and students), program, and identification. Screening and identification policies have been affected, and an estimated 10 percent of the students between the schools meet the criteria for deaf-blindness.

Goal #6: Delivery of Training on Transition Issues for Youth with Deaf-Blindness.

Objective #1: To improve state level planning and policy development for transition of youth with deaf-blindness.

Objective #2: Enhance the participation of youth with deaf-blindness and their families in achieving successful transitions from school to work and community living.

Objective #3: Provide professional development and training that will prepare youth with deaf-blindness for transition.

One of the great successes of the grant cycle is the development and implementation of the Transition Resource Team (TRT). After identifying an expressed need and examining several models, the team formed in 1994. With an emphasis on maximizing statewide transition initiatives (the State Transition Interagency Committee and the Community Transition Interagency Committees), the group has met three times. With geographic and professional diversity represented in the group of 30, there is potential for statewide impact. The team also includes students with deaf-blindness, parents, and adults with deaf-blindness. While most of the efforts were on a statewide and organizational level, the impact made its way to families and students by the end of the grant cycle and looks to continue.

Goal #7: Develop and Implement Procedures to Locate and Track Individuals with Deaf-Blindness.

Objective #1: To develop and implement procedures that will identify all individuals with deaf-blindness in the state.

Objective #2: To implement a systematic process of accurately collecting and sharing census information among state agencies.

The census continues to increase, but the rate of increase has slowed. Before this grant cycle, child count was at 208 (birth to 22). By the end of the cycle, the child count was 258. By stark contrast, the state December 1 unduplicated count had only 22 registered in the state. Information was also sent to Special Education Directors using electronic mail in addition to posted mail. This improved the response time and also the rate of response. Efforts collaborated with the Vision Screening Project and State Services for the Blind.

Goal #8: Develop a Linking System with Other Part C, Section 622 Coordinators and Projects to Collaborate on Procedural Development of Project Objectives.

Objective #1: To continue to work with TRACES to obtain technical assistance in the areas of functional assessment, self-advocacy, early intervention, and transition.

Objective #2: Disseminate project information to other Part C, Section 622 Coordinators.

Objective #3: To attend national Project Director's meetings.

Objective #4: To participate in staff development opportunities which will enhance the implementation of project goals.

The Project worked with TRACES staff in the areas of the Great Plains Regional Alliance, Usher Syndrome screening/identification, regional strategic planning, functional assessment, and program planning. The regional representative also came to Minnesota in 1993 to work on long-range planning. The project also dialogued and collaborated with other state 307.11 grants, especially those of the Midwest region. The annual Project Director's meetings was an excellent opportunity to disseminate information to other state projects as well as staying current on issues in the field. Staff development updated skills in the areas of communication, functional assessment, early identification, transition, and national resources (HKNC, AADB).

Goal #9: Develop and Implement First Responder Training for Emergency Care Procedures for Individuals with Deaf-Blindness.

Objective #1: To complete training program for First Responders.

Objective #2: To implement the training of trainers for the First Responder Program.

Objective #3: To provide families of individuals with deaf-blindness with alternative identification procedures.

The training module was completed and the materials produced for the training. Permission to use symbols was obtained from Mayer-Johnson for use on the communication board. Various prototypes were developed, in collaboration with State Services for the Blind. One of the major barriers to this training module is that the interagency commitments have changed multiple times over the life of the grant cycle. Some of our collaborating agencies changed personnel three and four times within the three year period. With materials developed, including the printing of a Braille/ symbol communication board. Training will continue during the upcoming grant cycle.

Goal #10: Build Linkages with the Intertribal Council and Indian Education Program for Minnesota.

Objective #1: To identify tribal administration systems including principle chiefs and education leaders on each of the four BIA reservations in Minnesota which have independent school programs.

Objective #2: To promote collaboration with the BIA entities listed above to enhance dissemination of program information, identification information, assessment availability, and determine direct service needs for all children and youth, ages birth through 22 years who are enrolled in BIA schools.

Objective #3: To facilitate development of direct services to children and youth with deaf-blindness ages birth through 22 years who are enrolled in BIA schools.

The objectives, as written in 1992, proved to be unrealistic for our state. Efforts

concentrated on building linkages and will continue to focus efforts there. Linkages were built with systems and personnel from other state agencies and initiatives to focus on the common goal of providing appropriate services to reservation lands. One of the major successes was the formation and commitment of Great Plains states to work together in this area. After the need was identified, it was difficult to locate many resources that were appropriate for the tribal nations of the Great Plains. The Great Plains Regional Alliance (GPRA) has been a wonderful resource, and the Alliance will develop resources to come out of this collaboration. This idea was the foundation for the pilot project written by South Dakota to continue working on this issues for the next four years, with an emphasis on identification and assessment.

VII. A Discussion of Problems and How They Were Resolved

Many of the major issues that impacted the project's effectiveness related to two primary areas, system inefficiency and staff turnover. Both of these areas have been addressed and a majority of these problems have been reduced or eliminated for the next four year grant cycle.

Staff turnover had a major impact on the Project. When this grant cycle started in the fall of 1992, new staff were hired in two key positions, the school and support specialist and the family support specialist. With the two staff that spend the majority of time in the field starting fresh at the same time, it took several months to establish rapport and good working relationships with the many parties with which the Project needs to interact. These relationships were built upon for the length of the grant cycle, and fortunately, these positions remained stable for the three year cycle.

The Director and Coordinator positions, although stable when the grant started the new cycle, changed soon after, and marked the first of several changes throughout the grant. The Project had four directors and three coordinators over the life of the grant. Stability occurred in the third year, when the family support specialist was promoted to the coordinator position and a new director was chosen. This stability continues with the same staff in place today. The working relationships are vital to the effectiveness and dissemination of information and resources throughout the state. The difference between a project that exists and one that thrives is the connections and working relationships that are built by the staff to the families, districts, teachers, interagency partners, and children throughout the state.

The other main barrier in this grant cycle was system inefficiency. The fiscal host was Intermediate School District #916. The district system of operating wasn't always in line with the goals or activities of the project. The district structure is to provide local service which wasn't always supportive to the structure of a Project that serves the state. Additionally, the support services offered operated on a school year time line, with a reduction of staff hours to process work and provide in-direct services in the summer months. Some invoices would take up to several months to pay, and this would damage relations with several vendors, contractors, and service providers that

worked with the Project. Great efforts were made to match the grant as written (to meet federal criteria) with the districts business office procedures. This system did not operate in the same way, nor on the same timelines, as federal projects. The efforts to meet the needs of both took a lot of time, energy and resources away from accompliishing the goals and activities of the grant.

This situation has been improved greatly by changing fiscal hosts for the upcoming grant cycle. The new host, Metro Educational Cooperative Service Unit, has a business office that is much more conducive to the operations of the Project. Timelines for payments and processing will be reduced greatly, and the environment links the Project with many other collaborative resources that will increase the impact of the Project.

In terms of program areas, the largest challenges were in the areas of Native American identification and services to children with deaf-blindness and the first responder's program. Some of this is to be expected. With any program or idea that crosses multiple agency or service provider lines, unexpected or unforeseen delays and obstacles are the norm. Additionally, each time that collaborative partners turn over personnel at collaborating agencies, time needs to be taken to develop new relationships and make sure that agreements and common goals remain in place.

VIII. Research or Evaluation Findings:

No research was done through this project. Components of evaluations are included in the areas of program in which they were accomplished.

IX. Project Impact.

The dissemination numbers are included in the goals and activities section, where numbers were collected.

X. Further information can be found at the ERIC clearinghouse, DB-LINK, and the Minnesota Department of Children, Families and Learning.

XI. The following report has also been sent to the ERIC Clearinghouse. The mailing address is as follows :

ERIC/OSEP Clearinghouse
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091.

FIRST
CLASS
STAMP

MINNESOTA DEAF-BLIND
TECHNICAL ASSISTANCE PROJECT
201 Capitol View Center
70 West County Road B-2
Little Canada, MN 55117

Please contact me regarding information on Deaf-Blind Technical Assistance project as follows:

____ Technical Assistance

____ "Children Linking Families" Events

____ Materials Resource Center

____ Family Support Network

____ Teacher Network

Name_____

City_____State_____Zip Code_____

Phone ( )_____

Detach and return this form to:

MINNESOTA DEAF-BLIND
TECHNICAL ASSISTANCE PROJECT
201 Capitol View Center
70 West County Road B-2
Little Canada, MN 55117

MDE
MINNESOTA DEPARTMENT OF
EDUCATION

MINNESOTA DEAF-BLIND
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A cooperative project between the
Minnesota Department of Education and the Northeast
Metropolitan Intermediate School District No. 916

MINNESOTA DEAF-BLIND TECHNICAL ASSISTANCE PROJECT

MISSION

The Minnesota Deaf-Blind Technical Assistance Project is a team of dedicated individuals committed to supporting services to children and youth with deaf-blindness throughout the state. Our vision for service is demonstrated through training and technical assistance, information sharing, and support services for families.

FEDERAL DEFINITION OF DEAF-BLINDNESS

"Individuals are deaf-blind or have dual sensory impairments if they have auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated in special education programs solely for children and youth with hearing impairments, visual impairments or severe disabilities, without supplementary assistance to address their educational needs due to these dual, concurrent disabilities."

According to the U.S. Office of Special Education, there are 8379 individuals with Deaf-Blindness from birth to 22 years. Minnesota has identified 208.

GOALS

1. Serve all public and reservation schools statewide.
2. Provide technical assistance and educational training.
3. Address early childhood issues on deaf-blindness.
4. Continue and expand a family support network.
5. Continue and expand interagency collaboration.
6. Maintain and update statewide census.
7. Promote ongoing communication with Deaf-Blind projects in other states.
8. Implement Emergency First Responder Training throughout the state.
9. Develop and disseminate resources to provide access to information/services

SERVICES AVAILABLE

1. "Children Linking Families" Family Enrichment Weekend

   The Minnesota Deaf-Blind Technical Assistance Project and the Minnesota Department of Education in cooperation with other state and local agencies and programs, provide weekend and workshop opportunities for families of children with deaf-blindness.

   These events include: Information sharing, respite, and recreation for families of children with deaf-blindness.

2. Training for educators, service providers, and families. Areas of training may include:
   - ✧ Communication
   - ✧ Orientation and Mobility
   - ✧ Independent living skills
   - ✧ Early childhood intervention
   - ✧ Health care issues
   - ✧ Transition planning
3. Technical assistance, based on individual needs and requests, is provided in homes, schools, and programs for educational personnel, families, and others.
4. Teacher network: A network of teachers of students with deaf-blindness throughout the state, linking them via workshops and telephone to be resources for each other.
5. Family support network: Provide opportunities for families to network informally.
6. Materials Resource Center: Media and publications for families, educators, and service providers are available for loan.
7. Maintenance of a statewide census of deaf-blind infants, toddlers, children and youth (0 to 22) with deaf-blindness.
8. Newsletter on state and national issues pertaining to deaf-blindness.

MINNESOTA DEAF-BLIND TECHNICAL ASSISTANCE PROJECT
201 Capitol View Center
70 West County Road B-2
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☎ Tel: (612) 779-5837
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CHILDREN LINKING FAMILIES
201 CAPITOL VIEW CENTER
70 WEST COUNTY ROAD B-2
LITTLE CANADA MN 55117

PLACE STAMP HERE

CHILDREN LINKING FAMILIES
is a program sponsored by the
Minnesota Department of Education.

For more information, contact
Minnesota Deaf-Blind
Technical Assistance Project
201 Capitol View Center
70 West County Road B-2
Little Canada, MN 55117
(800) 848-4905 (V/TTY)

CHILDREN LINKING FAMILIES

MISSION *Children Linking Families (CLF) is committed to provide support to Minnesota families of children with hearing and vision loss. CLF will provide ongoing social and education opportunities for families and empower parents to advocate for their children.*

CLF PROVIDES:

- ❑ A family-enrichment weekend once a year
- ❑ Family workshops three times a year
- ❑ Monthly family newsletter
- ❑ Volunteer companions for children
- ❑ Guest speakers

Kids are matched with volunteers at CLF events.

Parents at the CLF weekend.

PARENTS' FAVORITE PARTS OF CLF EVENTS

- *"The opportunity to meet and share with other parents"*
- *Speakers*
- *Relaxing*
- *The Talent Show*
- *The Food*
- *"Nice to see old friends again."*

Please call if you have any questions or would like information about upcoming events.

Kids showing off their talents at the CLF weekend.

Name _____

Address _____

City _____

State/Zip _____

Phone _____

Vol. 1, No. 1
January 1996

The DeafBlind Inquirer

The Concept Behind "The DeafBlind Inquirer"

By Eric Kloos

Welcome to the first edition of *The DeafBlind Inquirer.* The idea for this community-wide newsletter is to combine our information and resources to reach the entire community with one newsletter. Many people who shared this idea got together to discuss the concept of a newsletter, including representatives from the Minnesota DeafBlind Association, several parents, four state agencies, two private service providers, and several DeafBlind people.

The main priority for putting this newsletter together was to provide all com-munity members (DeafBlind people, families, service providers, teachers, agencies, volunteers, and friends of the community) with equal access to information at the same time on all kinds of issues that are of inter-est to the community. Not all information will be relevant to all people, but all the information is there for you to choose your areas of interest.

This is our first attempt. We know this will not be a perfect first issue. Please share your ideas with anyone involved in this first try or let us know if you are interested in sharing your talents by working on this project in the future.

In this issue, and those in the future, you will find a variety of topics. Some will be stories of personal experience. Others will focus on specific topics such as transportation, interpreter services, education, family issues, community services, national perspectives, and issues from around the state. There is also a list of upcoming events.

I hope this is enjoyable and informative for you and please let us know what you think of this first attempt.

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MDBA

Hello. My name is Tricia Borman. I am the president of the Minnesota DeafBlind Association (MDBA). MDBA is a nonprofit organization run by DeafBlind people for the DeafBlind community. We are still a young organization, established in 1981. Our board includes members who are DeafBlind, Deaf, and Hearing.

We provide monthly educational workshops and community integration events for the DeafBlind community. Our monthly meetings give DeafBlind people an opportunity to meet new friends, share advice and helpful information. The next two meetings will be on February 10 ("Problem Solving and Conflict Resolution") and 24 ("Money Management") from 1:00-5:00 p.m. We serve a lunch and everyone is welcome. Please give us a call if you are planning to attend, 603-2001 (TTY) or 646-8342 (V). We are at 1600 University Avenue West in St. Paul, on bus route #16.

Summary of Recent Events

In October, MDBA had to cancel the workshop due to the MCTO bus strike. It made it extremely difficult for the DeafBlind to come. Metro Mobility was overbooked and full. There were very limited options for our members to get around. The board felt that canceling it would be best. The workshop was rescheduled for January 20, 1996. The topic was John Walsh, Director of MCIL and MDBA had a membership meeting.

In November, MDBA had the annual Thanksgiving Banquet at the Normandy Inn. We had dinner and then a program consisting of a guest speaker, John Clark, who spoke of his experiences being DeafBlind, how he makes it positive. We also gave out several awards. The Ted Mahoney Award went to Ron LeClaire (DeafBlind), Volunteer of the Year Award to Cheryl Maire, Volunteer of the Year Award to David Williams, and a special award to Cori Giles for being our past consultant. We also had a raffle and a silent auction. We were helped by FIND Inc. and the Minnesota DeafBlind Technical Assistance Project.

In December, MDBA and FIND Inc. cosponsored a Holiday Party. We had potluck dinner and time for socializing, then we had games. The "Dice" game with prizes, "Guess How Many M&Ms in the Jar" game, and the "Smell" game (guess what things smell like). Then Santa (Ron LeClaire) came and passed out gifts from the gift exchange. All had an enjoyable time.

Hope to see you at our next event!

The DeafBlind Inquirer
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The DeafBlind Inquirer is brought to you by the collaborative efforts of the Minnesota DeafBlind Association, State Services for the Blind, Deaf and Hard of Hearing Services Division of the Department of Human Services, as well as Dr. Davenport, friends, and family of the DeafBlind community, with the Minnesota DeafBlind Technical Assistance Project and FIND Inc., in leadership roles. Our goal is to bring to you the latest information available about the DeafBlind community and affiliated organizations. You are welcome to submit articles but the editorial board reserves the right to review and edit. Views expressed do not necessarily reflect those of the above-listed agencies or individuals. While you are welcome to reproduce material from this newsletter, we ask that you acknowledge us as the source and send us a copy.

The DeafBlind Inquirer has selected the term "DeafBlind" as the word of choice by the Minnesota DeafBlind community for use in this newsletter. The term DeafBlind replaces the use of these terms: Deaf-Blind, Deaf/Blind, Dual Sensory Impaired, Hearing and Vision Loss, deaf blind, etc.

Editorial board members: Mary Hartnett (FIND Inc. Interim Executive Director), Eric Kloos (MN DeafBlind Project), Sally Prouty (FIND Inc. CDP Director), and Pam Morris.

Interpreting for DeafBlind Students

By Lee Clark, M.A.

Are there any formal interpreting training programs that include the values and needs of DeafBlind people in the United States? Actually, no, but DeafBlind communities around the country are working out an answer to this question. Currently, there is a BIG NEED for highly qualified interpreters in educational programs for youth and adults who are DeafBlind.

I am raising one important question—should an interpreter be permitted to change roles while working with the DeafBlind student in and/or out of the classroom, one role being that of the interpreter, another role as tutor, and another role of a support service provider? DeafBlind people and parents of DeafBlind children are frustrated by the limits interpreters put on the scope of services they are willing to provide. My hope is that through training, and open and honest dialogue, we in Minnesota will begin to face this difficult question.

I would like to share wonderful news with you! Minnesota is very fortunate to offer three educational workshops for interpreters who work with DeafBlind students. The first educational workshop (supported by the Minnesota DeafBlind Technical Assistance Program, FIND Inc., Minnesota DeafBlind Association, Metro SPLICE, and the College of St. Catherine-Minneapolis) was offered and conducted in American Sign Language by Lee Clark, who is DeafBlind, and Linda Hanke, who provides interpreting services in the DeafBlind community. The first workshop was held on November 11, 1995, and the second on January 27, 1996. The third workshop is tentatively set for March 2, 1996. All workshops cover basic manners and etiquette pursuant to the "DeafBlind world" such as identifying yourself by name before signing, using modified turn-taking techniques, wearing clothes that contrast with the interpreter's skin tone, and so on.

The first workshop covered the definition of DeafBlind, vision, establishing the interpreter-student relationship, psychosocial aspects of student life, and a simulation of a secondary classroom activity. Workshop participants had opportunities to develop knowledge and skills needed to provide communication services to DeafBlind students. Participants who completed the first workshop successfully demonstrated their ability to interact and communicate effectively with DeafBlind students using culturally appropriate basic manners and with an understanding and a respect for an individual's right to determine his or her own needs. Participants were encouraged to return to the school districts and to continue learning by observing DeafBlind students in classroom activities or in natural settings. The second workshop covered DeafBlind culture, etiologies of being DeafBlind, modifying interpreting services (the intervenor model), and problem-solving difficult situations.

I want to express my wholehearted thanks to Eric Kloos, Sally Prouty, and others for their strong support of this idea and to all the people and interpreters for makng these workshops successful.

For more information, please contact Sally Prouty, FIND Inc., at (612)871-4788 (V/TTY) or Eric Kloos, Minnesota DeafBlind Project, at (612)490-0058 x106 (V) and (612)490-7442 (TTY).

FIND Update

Minnesota State Academy for the Deaf (MSAD) DeafBlind Youth Support Group

By Ryan Bondroff

Last December, a DeafBlind Youth Support Group was formed at the Minnesota State Academy for the Deaf. FIND Inc. and MSAD established this group to provide a relaxed atmosphere for MSAD students to discuss issues related to DeafBlindness. I facilitate the group with Carmen Adams, the MSAD social worker. The students provide emotional support for one another, meet guest speakers, discuss educational issues, and attend social activities together. The Minnesota Deaf and Hard of Hearing Services Division recently awarded FIND Inc. a grant to continue the support group. This is an exciting time for all of us.

The first support group meeting proved to be a successful event, so we decided to meet monthly. Last March we invited Barry Segal to give a presentation about his life story and had a lunch meeting which the MSAD students enjoyed.

Ryan Bondroff signs with students

FIND Inc. sponsors a Community Integration Program for adults who are DeafBlind. This group meets bimonthly and provides them with educational and social opportunities. In April, five MSAD support group students participated with the adults in a tour of the Ford motor plant in St. Paul and a dinner followed at Baker's Square. The kids really enjoyed this activity, especially watching how the truck tires were tested spinning on rollers.

In addition to the social opportunities provided, the kids will also have the potential to develop leadership and teamwork skills, become advocates for themselves, and understand about being DeafBlind and accept who they are.

Our future plans include an excursion with Wilderness Inquiry in the summer of 1996. We also plan to be involved in an educational workshop for all MSAD students as well as give presentations to schools and encourage other DeafBlind students to take an active role in the support group. In the meantime, we all look forward to the support group at MSAD.

(Editor's note: Ryan Bondroff works as the Lead Program Instructor for Deaf and DeafBlind adults at the Cedar Avenue Apartment Learning Program within FIND Inc. Ryan is DeafBlind with Usher Syndrome.)

FIND Update, continued on page 5

FIND Update, continued from page 4

DeafBlind and Deaf Community Bridge Project

The DeafBlind and Deaf Community Bridge Project was started in the spring of 1995 and meets once each month. The project's mission is to link members of the DeafBlind and Deaf communities through education of DeafBlind people's unique needs and desires, and to increase accessibility. One of the goals is to build a bridge between the DeafBlind and Deaf communities by educating members about DeafBlind culture, needs, and attitudes to increase mutual understanding and encourage more social opportunities. The project also hopes to increase accessibility to Deaf-sponsored events. In addition, the project hopes to sponsor events that will bring the two communities closer together. Contact Barry Segal through FIND Inc., at (612)333-6419 (TTY) for more information.

Members of the Bridge Project

The Children's Discovery Project

Welcome to the first edition of *The DeafBlind Inquirer.* My name is Sally Prouty and I am the Children's Services Director at FIND Inc. I am the parent of three children. Our middle son, Andrew, has CHARGE Syndrome, causing his vision and hearing loss. For the past 2-1/2 years, I have been working on the Children's Discovery Project (CDP), matching Co-Active Learning Partners with DeafBlind children throughout Minnesota. The Minnesota DeafBlind Technical Assistance Project (TAP), in collaboration with FIND, is providing my services as a parent liaison. In this new role with TAP, I will also assist in the Children Linking Families weekend and workshops.

This column is for you! Please contact me with any comments or suggestions on how I can make it more meaningful for you. Please contact me if you would like more information or are interested in enrolling your son or daughter in CDP. Currently, 20 children are being served through the program and our goal is to serve more.

Rachel Eggert and her past Learning Partner, Kristin Koehner

8%...12%...80%...

How do children learn? You might be surprised to know that only 8% of what children learn comes to them directly. Group learning (secondary learning) fares little better at 12% of what gets in kids' heads. Kids gather the majority (80% of their information) without even trying—by simply overhearing or "overseeing" it (tertiary learning). Consider the implications for our DeafBlind children!

According to John and Jacquie McInnes, DeafBlind children must be taught everything firsthand because they don't benefit from secondary or tertiary learning. The amount of firsthand learning required depends upon the amount of vision and hearing loss they experience. The more loss, the more firsthand learning is necessary.

Education Update

New Minnesota Department of Children, Families, and Learning

By George Holt

On October 1, 1995, the Minnesota Department of Education was transformed to be the Minnesota Department of Children, Families, and Learning. Bruce Johnson was named to be the Commissioner of the new department. The legislation to create this change envisioned a "single-stop" service center for children and their families. Over the next year, activities and services from other departments will be transferred to the new department. At the time of this writing, major components of the new department are still being developed. In future issues of this newsletter, specific components and activities will be itemized.

New Curriculum for Students Who are DeafBlind

The American Foundation for the Blind has developed a new curriculum which is designed to meet the needs of students who are dual-sensory impaired.

The American Foundation for the Blind has developed a new curriculum which is designed to meet the needs of students who are dual-sensory impaired. This new curriculum, entitled "Hand in Hand," is an easy-to-follow packet intended to assist a willing teacher to become a more effective instructor. The four volumes, plus a videotape program, provide a quick access to needed information. These materials emphasize the communication and mobility skills crucial to independence and provide important information to help service providers do their jobs more effectively.

The basic curricula has two manuals and 20 modules. The Table of Contents provides a good overview of the areas discussed. Three other components of the curriculum include a one hour video, a collection of 27 journal articles, and an in-service training guide. The video is a one hour presentation featuring individuals who are DeafBlind and their families, as well as instructors. It is an introduction to working with DeafBlind students and contains practical suggestions and valuable insights. The journal articles are on topics of communication, orientation and mobility, functional skills, and implications of various etiologies and instructional strategies and intervention issues. The in-service manual provides structured information and suggestions for using the "Hand in Hand" materials in training sessions, including assessment and evaluation.

The Minnesota DeafBlind Technical Assistance Project has purchased multiple copies of the "Hand in Hand" curriculum; copies may be found at the Resource Center for the Blind and Visually Impaired, Resource Center for the Deaf and Hard of Hearing, and the Regional Low Incidence Facilitators. Copies are also available for review from the Minnesota DeafBlind Technical Assistance Project.

Human Services Update

Department of Human Services Update

In the spring of 1995, the Department of Human Services' Deaf and Hard of Hearing Services Division (DHHHSD) awarded two-year contracts to three nonprofit organizations that serve DeafBlind people. The Duluth Lighthouse of the Blind in Duluth, the Hearing and Vision Loss Outreach Program of the Children's Discovery Project, and Minnesota DeafBlind Association will be offering educational support and community integration opportunities. FIND Inc. will be providing case management services, facilitiating a DeafBlind support group, offering services to DeafBlind children and their family members, and establishing a bridge between DeafBlind and Deaf individuals.

This year, DHHHSD staff organized a "Forum for DeafBlind Service Providers," whereby service providers from across the state gathered to identify and prioritize service needs for DeafBlind consumers. As a result of the meeting, two work groups were established to begin addressing these needs. One group is focusing on centralized communication issues and the other group is focusing on services to DeafBlind adults. Individuals interested in joining a group are encouraged to call Marie Koehler at (612)297-3640 or (612)297-1384 (TTY).

What's Up With Who's Who

Mary Dykstra, Joanne Wiltscheck, Susan Shogren-Smith, and Ryan Bondroff were selected to attend the national DeafBlind training at Northern Illinois University, January 8-26, 1996.

Congratulations to Linda Lingen, who has been appointed director of Career/Independent Living Services at Minnesota State Services for the Blind.

Linda Hanke, Lee Clark, Sally Prouty, and Susan Shogren-Smith have been chosen to present at the Conference on DeafBlindness in Vancouver, B.C.

Congratulations to Lee Clark, who has been appointed DeafBlind Specialist for the State of North Carolina, beginning in April.

SSB Provides Cross Country Ski Opportunity for DeafBlind Children

Curt Johnson of SSB announces that the Ski for Life Program, typically for Blind children, has been expanded to include children who are DeafBlind. With advance notice, Curt will provide volunteer ski instructors/guides for each DeafBlind child who is interested. This program teaches a lifelong leisure skill in which the entire family or friends can participate

SSB will provide a guide and hot chocolate in the park's warming house. You provide warm clothes and energy to ski. Skis are available to rent at the warming house, as well.

The program is scheduled to run four Saturdays in January and the first two Saturdays in February. Come, have fun, and enjoy the great Minnesota outdoors.

Where: Phalen Golf Course in St. Paul (off Hwy. 61 and Maryland Avenue)

When: Saturdays, 2-4 p.m.

Sign up and information: Call Curt Johnson, SSB, 642-0790.

DeafBlind Project Update

By Eric Kloos, Project Coordinator

Autumn has brought about may changes. In addition to the expected leaves changing colors, the Minnesota DeafBlind Project has also experienced many changes. Previous staff members Jo Hausken and Esther Tangen are no longer with the Project. Jo left in August to take a position with Intermediate School District #916. Esther retired on September 30 and is currently relaxing in Florida.

We started a new funding cycle on October 1 and started by moving offices. We are currently located north of St. Paul on Lexington Avenue (between Highways 36 and 694). Our address is: Minnesota DeafBlind Project, 3499 Lexington Avenue North, St. Paul, MN 55126.

The toll-free number remains the same (1-800-848-4905), but our local numbers have changed to 490-0058 x106 (voice) and 490-1442 (TTY).

Several people have asked if I feel all alone this year, with two long-time staff members leaving, but actually, I have a strong group of people involved and supporting Project activities. George Holt, from the Department of Children, Families, and Learning, is in his second year as Project Director. His consistent leadership and support are a great asset to the Project. The support staff at the new office have been tremendous. The support staff person working with the Project is Jan Schmitt. Feel free to contact her if you need help and I am not in the office. Her phone numbers are 490-1442 (TTY) and 490-0058 x116 (voice).

We are continuing to support Sally Prouty and the Children's Discovery Project. We believe our continued collaboration is benefiting children and families around the state and we plan to continue, and expand, our collaboration.

I am also excited to announce an exciting, positive new addition for this year. We will be working with Dr. Sandra Davenport on several projects. Dr. Davenport is a pediatric geneticist who is internationally known for her work with various syndromes such as CHARGE and Usher. We are happy that in collaboration with the Minnesota DeafBlind Project, Dr. Davenport will be available for questions and consultation every Tuesday from 2-4 p.m. at her office (831-5522). This is available for parents, teachers, and students.

I would also like to announce the dates for the 1996 Children Linking Families (CLF) weekend. It will be held at Ruttger's Bay Lake Lodge (for the fourth consecutive year), May 17-19, 1996. Mark your calendars now and family applications will be out near the end of February. If you are interested in volunteering for the weekend, please contact Eric Kloos at (612)490-0058 x106 (voice) or (612)490-1442 (TTY).

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New Videotape Available

"Gross Motor Development in Children with CHARGE." The video costs $20 + $2.50 shipping & handling. This video shows children from 2 to 24 years. All but one have inner ear balance problems. The tape shows how the younger children crawl and move about prior to walking. As the children get older, their walking becomes progressively steadier.

To order, call Dr. Sandra Davenport ((612)831-5522) or contact: The CHARGE Syndrome Foundation, 2004 Parkade Blvd., Columbia, MO 65202, or (314)442-7604.

On the Internet

By Kathie Anderson

Hi, everybody. I am writing this like an electronic e-mail message. Actually, this article was submitted by e-mail. I am writing about the new, exciting newsgroup on the Internet called DEAFBLND (notice the letter "i" is missing in DEAFBLND. This is because there is a maximum of eight characters to create a file name of a group).

DEAFBLND list is a group of people from all over the world who want to share information with one another on issues related to DeafBlindness via the Internet. These people include the DeafBlind community, parents, spouses, friends, and professionals who may or may not be DeafBlind. All these people have one thing in common—their interest in DeafBlindness. I have received messages through the DEAFBLND list from Canada, Sweden, the United Kingdom, New Zealand, Australia, Hong Kong, Israel, and various places in Europe. You can just read information, respond to conversation, or send a private e-mail to individuals on the DEAFBLND list. People can learn from you through the DEAFBLND list. I am here to tell you how simple it is to sign on to the DEAFBLND list.

How to Sign On to the DEAFBLND List

(Note: Commands may vary according to your server type.)

(1) Compose an e-mail to: "LISTSERV@FSTR.WOSC.OHE.EDU"

(2) Leave SUBJECT blank

(3) In MESSAGE AREA type: "SUBSCRIBE DEAFBLND (your first and last names)"

(4) Send it. Within a few minutes to a half hour, you will receive a message from the MAISER@FSTR.WOSC.OSSHE.EDU stating your request has been confirmed.

(5) That's it! You are now officially signed on the DEAFBLND list.

(6) To post, use DEAFBLND

I've found another group called RPLIST on the Internet. This group includes individuals with Usher Syndrome (Types 1, 2, and 3) from all over the world. Signing on is similar to the DEAFBLND list.

(1) Compose an e-mail to: "LISTSERV@TR.WOSC.OSSHE.EDU"

(2) Leave SUBJECT blank

(3) In MESSAGE AREA type "SUBSCRIBE RPLIST (your first and last names)"

(4) Send it. You are officially signed on!

If you have any questions regarding the DEAFBLND list or RP list, feel free to write me at my e-mail adress: "ande1224@gold.tc.umn.edu".

Happy e-mailing!

Myosin VIIa Defect is Cause of Usher Type 1b

By Sandra L.H. Davenport, M.D.

In March of 1995, the gene for Usher Syndrome Type 1b was discovered. All people with Usher Type 1 are born deaf and, as far as we know, they are all born with vestibular dysfunction, which means they have balance problems, too. Both halves of the inner ear do not work. The gene types were named 1a, 1bc, and 1c, on the basis of which gene was discovered first. Type 1a was found in France and Type 1c was found in the Acadian population of Louisiana. So far, approximately 3/4 of the people in the world with confirmed Type 1 have Type 1b.

At the American Society of Human Genetics meeting in Minneapolis in October 1995, information about the Type 1b gene was presented by Dr. Tama Hassan and her colleagues at Yale. The Type 1b gene codes for a protein called Myosin VIIa. When that was discovered in March, researchers predicted that the faulty myosin would be involved in abnormal ciliary function. Cilia are the "hairs" on the sensory hair cells of the inner ear and are also present in a different form in the sensory cells of the eye retina, which are called the rods and cones. This prediction about ciliary involvement was probably wrong for this particular type of Usher but may be right for another type. In the eye, the special type of myosin found in Type 1b is only found in the RPE (retinal pigment epithelium), which is the layer right next to the sensory cells. One job of the RPE is to "eat" (phagocytose) the waste products of the sensory cells. Another is to move the sensory cells appropriately in different lighting. In the ear, we know that myosin is in the sensory cells themselves. Exactly what it is doing there is not yet known.

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Calendar of Events

FEBRUARY 1996

3 State Services for the Blind Advisory Board Meeting. 10:00 a.m.-2:00 p.m. 2200 University Avenue #200, St. Paul.

6 DeafBlind Interpreting Class. Taught by Lee Clark and Linda Hanke through the Health Care Interpreter Program at the College of St. Catherine. For more information, call (612)690-7777.

8 DeafBlind Connection Meeting. MSAB.

10 Hartmann and Hallet Open Captioned Movie, "GoldenEye," 3:30 p.m., information line 929-3381.

28 Helen Keller Team Meeting. Call Ryan Bondroff, FIND Inc., at (612)333-6419 (T).

MARCH 1996

2 SSB Advisory Meeting.

2 Interpreting for DeafBlind Students Workshop #3, Metro ESCU. Call Eric at (612)490-0058 x106.

7 DeafBlind Connection Meeting.

9 Hartmann and Hallet Open Captioned Movie, "Mr. Holland's Opus," 3:30 p.m., information line 929-3381.

9 DeafBlind parent event, St. Thomas University, call Eric 490-0058 x106.

15 16 17 Midwest Bowling Tournament. Southtown Lanes. For more information, call Jose Herrera at (612)536-8781 (TTY).

22 Minnesota DeafBlind Technical Assistance Project Advisory Council meeting, 9:00 a.m-4:00 p.m., Metro ESCU, 3499 Lexington Avenue, St. Paul.

27 Helen Keller Team Meeting. Call Ryan Bondroff, FIND Inc., at (612)333-6419 (T).

MAY 1996

8 9 10 11 Conference on DeafBlindness: "Living and Learning: A Lifelong Adventure." Held in Vancouver, British Columbia, Canada.

17 18 19 Children Linking Families Weekend. Rutger's Resort in Brainerd, MN.

DeafBlind Contact Organizations & Service Providers

• **Minnesota DeafBlind Project** provides technical assistance, training, information sharing, support group, and support services for DeafBlind children and their families. Sponsors Children Linking Families workshops, weekend. Library of books and videotapes on DeafBlindness. Department of Children, Families, and Learning. Contact Eric Kloos at (612)490-0058 x106, (612)490-1442 (TTY), or 1(800)848-4905; fax (612)490-1920; e-mail MNDB@GTEENS.COM.

• **Minnesota DeafBlind Association** is a consumer organization of DeafBlind people. MDBA conducts workshops and luncheons every third Saturday, 1:00-5:00 p.m., January through May and September through December at their new office located at 1600 University Avenue, Suite 10, St. Paul, MN. Call the MDBA office at (612)603-2001 (TTY), (612)646-8342 (Voice), or (612)603-2006 (fax).

• **MN Department of Human Services Regional Service Center** provides information and referrals. The RSC Library provides short-term loans of adaptive equipment such as TTYs with large visual display, assistive listening devices, and vibrating wake-up alarms. Also available from the Equipment Distribution Program (housed within the RSC) are long-term loans of assistive telephone equipment including TTYs with large visual display, amplified phones with large number pads, and brailing TTYs. Located in St. Paul, Crookston, Virginia, Wilmar, St. Cloud, and Duluth. Phone (612)296-3980 (V), (612)297-1313 (TTY answering machine), or (612)297-7155 (fax).

• **The DeafBlind Connection**, the Academy for the Deaf and Academy for the Blind in MN meet to improve services for the 10% or more of DeafBlind student population on their campuses. Call Elaine Sveen at MSAB, (507)332-3226 or (507)332-3631 (fax).

• **Duluth Lighthouse for the Blind, Hearing and Vision Loss Program** assist any age person with hearing and vision loss. Assessment of needs, referral to other resources, training, and follow-up. Services for professionals include consultation regarding client's needs, staff training, and coordination of services. Call Joanne Wiltscheck at (218)624-4828, (218)624-4479 (fax).

• **State Services for the Blind** provides vocational counseling services, including adjustment to blindness, employment, and independent living skills for DeafBlind consumers of all ages. In addition, the communication center provides print in alternative format: tape, braille, Radio Talking Book, and Dial-In News. Call Linda Lingen at (612)642-0504, (612)649-5927 (fax).

• **Department of Human Services, Deaf, and Hard of Hearing Services Division** facilitates Deaf, Hard of Hearing, and DeafBlind individuals' access to Minnesota's human services system and assists Minnesota Deaf, Hard of Hearing, and DeafBlind citizens to attain the maximum degree of self-sufficiency possible, consistent with their individual goals and capabilities. Program Planner also responsible for the development and monitoring of grant contracts. Contact Marie Koehler at (612)296-8589.

• **Sandra L.H. Davenport, M.D., C.M.**, sensory genetics/neuro-development, is an internationally known specialist in DeafBlindness. Training and consultation. She is available every Tuesday from 2:00-4:00 p.m., for free information and referral. 5801 Southwood Drive, Bloomington, MN 55437-1739; (612)831-5522, (612)831-0381 (fax), or Internet address: slhd@maroon.tc.umn.edu

• **FIND Inc.** runs programs that provide opportunities for DeafBlind children and adults to live independently. Minneapolis highrise-based Cedar Avenue Program teaches independent living skills and Community Support Services teaches independent living skills in DeafBlind people's homes. Call Lisa Carlson or Diane Lentsch at (612)333-0907, (612)821-5403 (fax), or e-mail address MNFIND@GTEENS.COM.

• **Helen Keller Team** is a group of DeafBlind students from Minnesota State Academy and Minnesota State Academy for the Blind who meet to support each other, educate peers, and develop leadership skills. Call Ryan Bondroff at (612)333-1649, (612)871-5403 (fax), or e-mail MNFIND@GTEENS.COM.

• **The Bridge Project** meets monthly with members of Deaf and DeafBlind communities to bring them closer together. Sponsored by FIND Inc. Call Barry Segal at (612)333-6419, (612)871-5403 (fax), or e-mail MNFIND@GTEENS.COM.

• **Children's Discovery Project** matches one-on-one Learning Partners with DeafBlind children for 16-20 hours each month to develop independent living skills. Provides respite for parents, training for families, educators, and families. A FIND program. Call Sally Prouty, (612)871-4788, (612)871-5403 (fax), or e-mail MNFIND@GTEENS.COM.

Parent Pages
For parents of children who have vision and hearing loss
Volume I, Issue 5 DECEMBER 1995

My First Experience with a DeafBlind Person

By
Ryan Bondroff

Ryan, on a recent trip to San Francisco.

In the fall of 1986, during my Junior year at the Model Secondary School for the Deaf (MSSD) in Washington, DC, I was very much in denial, and blamed my parents for giving me Usher Syndrome.

I was struggling with my life so I went to see the Specialist for Disabled Services at MSSD. She mentioned the name of a successful, well known guy named Art Roerig who worked at nearby Gallaudet University and is DeafBlind.

I asked the Specialist for Disabled Students many questions about what it is like to be totally DeafBlind, so she encouraged me to meet Art. Initially, I hesitated, but finally got up my nerve and made an appointment.

The morning of the appointment, I experienced many conflicting emotions from excitement, to fear, and anger. I had already experienced so many difficulties dealing with Usher Syndrome, I wasn't sure what to expect from this meeting.

Once I met Art, we talked for over two hours. Art told me of his experiences growing up and dealing with Usher Syndrome and being DeafBlind. I was so stunned to see how he went on to succeed in everything in his life, even though it was hard. He encouraged me to think positive and to show people that I can do anything I set my mind to do. He suggested not to become friends with people who do not accept DeafBlind individuals.. He advised me to make choices and not accept what is given to me. Art discussed the many issues I was dealing with such as driving and my vision loss.

After our long discussion, it helped break the wall of denial I had built inside me. I felt as though an "ocean of water" had cleaned out my system and that day I accepted my Usher Syndrome.

One issue that I could never accept was the fact that I had to stop driving. Regardless, in the spring of 1987, I took a Drivers Education class. After driving around campus two times, the instructor informed me that I could not drive. I was stubborn and begged my instructor to give me one more chance, but she refused. As a result, I was really angry, upset, and insistent that I **COULD** drive and would not let my instructor say no. She gave me choices: take Drivers Education somewhere else and others that I cannot remember - it was a blur! I demanded to take an eye exam at the Department of Motor Vehicles. I failed the exam and it was a **HUGE** blow to me. Right away, all the MSSD students knew that I could not drive.

Again, I went to see Art, this time to discuss driving. He slowly encouraged me to accept the fact that I was not able to drive at all, even though Art knew driving was and still is in my heart forever, just like all DeafBlind people.

Since then, I've talked to Art a number of times and he has given me a positive outlook on my life. My thanks go to Art for providing me with wonderful support, encouragement, patience, and effort. I will always think of him as a great role model in my life!

Note: Ryan Bondroff is the Lead Program Instructor at FIND, Inc.'s Apartment Living Program on the West Bank in Minneapolis. He is also the Co-facilitator of the MN State Academy of the Deaf (MSAD) Youth Support Group. Ryan graduated from Gallaudet University in Washington, DC in 1993 with a major in Psychology.

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COLUMNS

Editor's Corner

by
Sally Prouty, Children & Family
Services Director, FIND, Inc.

Mom was right: my eyes are bigger than my stomach! Or in this case, my well-intentioned goal of producing Parent Pages every other month was bigger than my time to do it. Reality hit home. Given my half-time position, a quarterly, rather than a bi-monthly newsletter seems more realistic. Mom would be proud!

My goal is to keep you appraised of the Children's Discovery Project as well as local and national information relating to DeafBlind children. Please keep in mind, we have a very diverse group of parents to serve. I try to provide information for everyone. If you find something that might be interesting,, call or mail it to me and I will include it in the next newsletter.

Here's what has been keeping me busy:

1. Developing new Discovery Plans for existing and new kids in CDP.

2.Planning workshops, "Interpreting for DeafBlind Students" *(Encourage your child's interpreter to attend these free workshops, see p. 6 for details)*

3. Grant writing for "Enhanced Training for Caregivers of DeafBlind Children with Emerging Communication Needs".

4. Developing and distributing a "Parent Needs Assessment" to help us and agencies deliver better services. *(free prize drawing, extended to 1-1-96.*

5. Working with the Perkins School for the Blind to bring out a group of professionals to do psychological testing on our DeafBlind kids.

6. Preparing and presenting at a statewide conference in St. Cloud about the Children's Discovery Project.

7. Attending I.E.P.s as requested by parents.

I want to thank you all for letting me serve you. I am by no means the expert in the field of children who are DeafBlind. I know all of you have your own expertise and I would like you to share that knowledge with other parents. I may be contacting on you to share your wisdom. (see back page). Please don't hesitate to call me as well. My phone number is 871-4788.

From the Other Corner

by
Eric Kloos, Coordinator
MN DeafBlind Technical Assistance Project

Autumn has brought about many changes. In addition to the expected leaves changing colors, the Minnesota DeafBlind project has also experienced many changes. Previous staff members Jo Hausken and Esther Tangen are no longer with the Project. Jo left in August to take a position with Intermediate School district #916. Esther retired on September 30, and is currently relaxing in Florida.

We started a new funding cycle on October 1, and started with a bang by moving offices. We are currently located north of St. Paul on Lexington Ave (between highways 36 and 694). The toll-free number has remained the same (1-800-848-4905) but our local number has changed to 490-0058 x106.

Several people have asked if I feel all alone this year, with two long-time staff members leaving, but actually, I have a strong group of people involved and supporting Project activities. The support staff at the new office have been tremendous. The support staff person working with the Project is Jan Smith. Feel free to contact her if you need help and I am not in the office. Her phone number is 490-0058 x116.

We are continuing to support Sally Prouty and the Children's Discovery Project. We believe our continued collaboration is benefiting children and families around the state, and we plan to continue and expand our collaboration.

I am also excited to announce an exciting, positive new addition for this year. We will be working with Dr. Sandra Davenport on several projects. Dr. Davenport is a pediatric geneticist who is internationally known for her work within various syndromes, such as CHARGE and Usher Syndrome. We are happy that in collaboration with the MN DeafBlind project, Dr. Davenport will be available for questions and consultation with you every Tuesday from 2-4 PM in her office (831-5522).

I would also like to announce the dates for the 1996 Children Linking Families Weekend. It will be held at Ruttger's Bay Lodge (for the fourth consecutive year) May 17-19, 1996. Mark your calendars now, and applications will be out near the end of February.

Happy Holidays!

CHILDREN'S DISCOVERY PROJECT NEWS

Kim Hoodie Named October/November Partner of the Month

Kim Hoodie has been selected Partner of the Month. Since starting her work with FIND, Inc. this past summer, Kim has become the Partner of three more children. She now works with two teenagers with Usher Syndrome, a seven and an eight year old.

Additionally, Kim has done Compensatory Skills Training with one of her CDP kids, 4 hours five days a week, throughout the month of August. She now continues this additional support for an additional 4 hours each week. This time is funded by the MN State Services for the Blind (see insert page) and is more intensive work than CDP. Because of the success we saw with Kim and her partner, we are now trying to expand services to other children in the transition years.

We thank Kim for all her hard work, for getting her Partner on the bus on a regular basis, for working with four CDP kids, and for showing initiative to find interesting activities for the CDP kids and for her flexibility in making sure the kids get what they need ... a learning experience that's fun!!

What is the most interesting experience you have had with the CDP kids?
With one of the kids, the State Fair was wonderful because there was an unlimited supply of machinery for him to look at. With the other Partner our walk at Eloise Butler Bird Sanctuary was great, the bog won him over.

What is your favorite aspect of Partnering?
Rediscovering the world through someone else's experiences.

Has being a partner had any effect on your future plans?
I really enjoy my interactions with the kids in the program. I hope to be increasing the time I work at FIND and CDP.

What advice would you give other Partners?
Stay animated and upbeat to try to see things from the child's perspective and be patient!!!! Enjoy the miracles at work!

Children's Discovery Project Update

A number of changes and opportunities have taken place at FIND and the Children's Discovery Project. Susan Shogren Smith has become the permanent Partner Coordinator for CDP. Susan comes to us as a parent of a Deaf-Blind child with wonderful advocacy skills. She also has great enthusiasm for CDP. I hope you will all get to know her.

On pages 4 and 5 of this newsletter you will see photos of our October 28 Pumpkin Party at Aamodt's Apple Farm. Nine CDP kids were able to participate with their Partners. Curt Johnson from SSB (see insert) joined us from SSB, as well as Beth Paul, a nurse and a few parents. The weather was in our favor as we carved pumpkins, tasted apples and toured the farm. It was a beautiful day, we hope you can join us next time.

The majority of the kids in CDP have a goal on their Discovery Plans to learn how to access and use the bus system. Susan has contacted MTCO and purchased fare cards for the Partners and kids on their weekly outings. This should help pave the way for more frequent and easy use of the bus system.

We have also arranged for a FIND, Inc. membership to the Science Museum of Minnesota. Due to this membership, CDP children and their Partners have access to reduced admission to the exhibits and Omni Theatre. (Remember, CDP children and Partners pay no admission to the Children's Museum)

Recently, we have been discussing the possibility of starting a CDP teen group. This could be a fun get-together: potluck, group hike, Mall of America, restaurant, etc. Many of the CDP kids have difficulty socializing with peers for a variety of reasons. We think this could be of great benefit to each of the 7 teenagers currently in the program. For those of you who are parents of teens, please call with your input.

Do you wonder what CDP kids have been doing in the community? Here is a sample: State Fair... the Renaissance Festival... the Children's Museum... swimming... Como Zoo... Community Ed. classes... the Wellstone kickoff rally...High school Homecoming. Walking in their neighborhoods... state capitol... Burnsville Fire Muster Parade... Playworks...library... stores... Toys R' Us.. MN Zoo... ECFE parties... learning the bus system.....

CDP Pumpkin Party

Aamodts Apple Orchard

October 28, 1995

BEST COPY AVAILABLE

BEST COPY AVAILABLE

EVENTS

SSB Hosts

"Continued Dialog with the DeafBlind Community" as to how SSB can adapt services to suite your needs.
When: December 6, 5-7 pm
Where: SSB, 2200 University
Call ASAP for interpreter!

Bowling

Stardust Bowling Lanes is providing the opportunity for children who are Blind or DeafBlind to experience bowling with the goal of developing a league if there is enough interest expressed.

They currently have leagues with adults and children who are blind, and adults who are DeafBlind bowling at this same time. You are welcome to join them.

Where: 2520 26th Ave. S Minneapolis
When: Saturdays at 9:30am
Cost: $4.00
Contact: Dawn, 721-6211 or Curt Johnson, SSB 642-0790

Courage Center Offers Sports and Recreation Programs for Deaf and Hard of Hearing Children

Friday night swimming 6:45-8:15. (pool is heated to 92 degrees and has railings and ramps for easy & safe access)

MN/Metro Jr. NAD (National Association of the Deaf) for students 7-12 grade. Call Matthew Anderson 521-8416.

Ice Skating,, Jan 15 ,1-2 pm
Burnsville Ice Center

For more information about these and additional programs Call Harvey Hoffman at 520-0405 tty, or 520-0481 V for specific information.

MDBA (Minnesota Deaf-Blind Association) Celebrates the Holidays

When: Sunday, Dec. 16, 1-5
Where: MCIL (MN Center for Independent Living), corner of University & Snelling in St. Paul.
Bring a dish to pass and a gift under $5.00 to exchange. For more information call Sally at 871-4788.

INSIGHTS Holiday Get-together

Where: New Brighton Family Service Center
400 10th St. NW
When: December 12

INSIGHTS is a parent information and student recreation program for blind and visually impaired kids of any age throughout the metro area. *(note: a CDP family and Partner regularly attend these activities and praise their effectiveness.)*

Carol Wagner Cherrier organizes the monthly events which have included horseback riding,, motivational speakers, MN Zoomobile, Discovery Zone trip, talent show, and panel discussions.

The group meets the 3rd Tuesday of every month from 6:30 to 8:00 pm. Children participate in structured craft activities with licensed teachers and volunteer girl scouts, while parents meet in a separate area to address predetermined topics. Q's: Call Carol 429-7293.

INSIGHTS Offers: "Successful Adults Share Experiences about Blindness"

Successfully employed persons and students will share their experiences and skills unique to their blindness, with parents, children, and all who are interested. They will share their success and failures, their personal experiences, and skills they have needed to succeed.

These panel discussions will take place throughout the school year in the nine county area. They have been arranged and sponsored by local vision teachers, parents and SSB.

Bring your children, they will enjoy a "take-apart night" complete with typewriters, hairdryers, hand mixers, etc. while you enjoy the speakers. Call Carol Wagner Cherrier if an interpreter is needed.

Where: Metro ECSU 3499 Lexington Ave. Arden Hills,
When: Jan. 16, 1996 6-9 pm
Q's?: Carol Wagner-Cherrier, 429-7293 Gwen Johnson or Curt Johnson, SSB

Interpreting for Students who are DeafBlind

Workshop II

Presented by: Lee Clark & Linda Hanke
When: Jan 27, 1996 9 - 3 pm
Where: To be announced

Sponsored by MN Deaf-Blind Project, FIND, Inc., MDBA, Metro ECSU. Call Eric 490-0058 x106, or Sally 871-4788.

Seventeen interpreters attended the first workshop in November and found it very helpful!!

BITS AND PIECES

Courage Center has a Toy Lending Library

that allows parents to borrow toys specific to their child's physical and/or sensory needs. Cost is $90.00/year, but scholarships are also available. Call 520-0471.

INSIGHTS Library

of Descriptive VideoTape Service (DVS) movie tapes. These video tapes show the movie (ie. Lion King) but also includes voice-overs describing visual information in the story. No special equipment needed, except a VCR. Call Denise Neisz at 767-9285.

SSB Provides Catalogue of Adaptive Devices

(Gift giving ideas!!)

The SSB store at 2200 University carries a wide variety of items for people who are blind or have limited vision. The store carries brailled and large print games, magnifiers, guides for writing, and other useful items for the kitchen and home. For a catalog and listing of devices, call **THE STORE** at 642-0777 or 1-800-652-9000.

Captioned TV

Have you ever wondered who pays for the captioning of TV programs? It is not included in original production costs of a show. In many cases it is an afterthought and separate funding is sought. The funding comes from corporate sponsorship and US. Dept. of Ed grants. When a corporation offers sponsorship, it gets an ad of its own at the beginning or end of the program or sometimes, at commercial breaks. When you notice this, write a note of thanks. Let the corporation know you appreciate their support. *(from SHHH News,95)*

The Bridge Project

Historically, the DeafBlind Community has felt alienated from the Deaf Community. FIND, Inc. has received grant money from the Department of Human Services, Deaf and Hard of Hearing Services Division to address this need. A committee consisting of Deaf and DeafBlind members is developing a "bridge" with the Deaf Community in strengthening understanding between the two groups. For more information, contact Barry Segal, of FIND, Inc.

The Helen Keller Team

A group of students from MSAD, who are DeafBlind, have enjoyed monthly get-togethers to express feelings related to limited vision. This energized group of students also plans to educate their deaf peers about vision loss, and how it affects communication and their lives.

This FIND, Inc. program is funded through the Department of Human Services, Deaf and Hard of Hearing Services Division. It is Co-facilitated by Ryan Bondroff (see page 1) and Carmen Adams of MSAD. Would you like to see a similar group initiated in the metro area? Call FIND, if you are interested.

Shriners Hospital Offer Free Services

The Twin Cities Shriners Hospital is a 40-bed ortho-paedic hospital providing high quality care to children with problems of the bones, muscles and joints. For more information, call 335-5300.

Quotable Quotes

"When you want to teach a person, you start from where he is and work from that position -- not from where you are."
-Thomas Aquinas

"If we did all the thing we are capable of doing, we would literally astonish ourselves."
-Thomas Edison

"Failure is success if you learn from it."
-Malcom Forbes

"Training is everything. The peach once was a bitter almond. Cauliflower is nothing but cabbage with a college education."
-Mark Twain

"Experience is the name everyone gives to their mistakes."
-Oscar Wilde

"No one can make you feel inferior without your consent."
-Eleanor Roosevelt

"Youth is wholly experimental.
-Robert Louis Stevenson

"My hand is to me what your hearing and sight together are to you. all my comings and goings turn on the hand as a pivot. It is the hand that binds me to the world of men and women. The hand is my feeler with which I reach through isolation and darkness and seize every pleasure, every activity that my fingers encounter."
-Helen Keller

Parent Needs Assessment

Win a free night stay at Hotel Soffitel when completing this survey! The deadline has been extended to 1-1-96. Please call if you have not received your copy. Call Sally 871-4788.

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This newsletter is for parents of all children and youth who have vision and hearing loss, regardless of age or ability. One purpose of this newsletter is to keep in touch. Do you have information to share with other parents? Do you have a particular idea that has worked? Do you know of a resource that others should know about? What have you found to be a particularly helpful technique? We would like to know! Send your ideas or items you run across that we can share in one of the four newsletters that come out each year.

This newsletter has been developed by the Director of Children and Family Services, Sally Prouty and made possible through the funding of the MN Deaf-Blind Project; the Department of Human Services, Deaf and Hard of Hearing Division; The Bush Foundation; the Emma B. Howe Foundation; and the St. Paul Foundation.

FIND, Inc.
2344 Nicollet Avenue, Suite 420
Minneapolis, MN 55404-3355

Functional Independence Training, Inc.
2344 Nicollet Avenue, Suite 420
Minneapolis, MN 55404 612/871-4788 (V/TTY)

October 31, 1995

OOOOPS!! Due to a mix-up with mailing, we have decided to delay the return date to Jan. 1, 1996 to accommodate those parents who did not receive the original letter and survey. Thank-you, Sally 11-28-95

Dear Parents,

Some of you already know me. I am the Director of Children's Services at FIND, Inc. (DeafBlind Services). I am also the parent of Andrew, a 14 year old boy who has CHARGE syndrome. Andrew is profoundly deaf and has vision loss combined with a variety of medical issues.

I am writing to ask you to take **ten minutes out of your very busy schedules** to complete this "Needs Assessment". It has been designed for you to give open, honest and constructive feedback while maintaining your confidentiality. With the results, we hope to fine-tune services and more effectively advocate for improved services for our children statewide.

As an incentive, we will have a **prize drawing** for those parents who complete and return the survey to us. Hotel Soffitel in Bloomington, has generously donated a **gift certificate for one "RENDEZVOUS ROMANTIQUE PACKAGE". This includes one weekend night stay, champagne, roses, chocolate truffles, his and hers satin robes, a French love poem and breakfast for two in your room the next day.**

In order to maintain confidentiality I have included a separate slip of paper for your name, address, and phone number to be entered into the prize drawing. Your survey remarks will be kept strictly confidential. Please return the survey and prize drawing information no later than **December 1** in the self addressed, stamped envelope enclosed.

I thank you in advance for the time you invest. Oh, just a warning, you may receive more than one copy of this letter and survey. I have enlisted the help of teachers to reach more families, and as a result you may receive duplicates. We need only one.

Sincerely,

Sally

Sally Prouty,
Director of Children's Services

Needs Assessment for Parents of Children with Vision and Hearing Loss

You are under no obligation to complete this survey. Please be aware that this information will be kept in complete confidence.

1. Child's Name (optional)_____ Age_____ Sex_____

Diagnosis_____

Describe vision loss_____

Describe hearing loss_____

Other issues_____

2. What organizations/service providers are you and your child currently working with? Are your child's needs being met? Please rate your satisfaction level by marking with a number on a scale of 1-10 (1=unsatisfied, 10=completetely satisfied).

_____State Services for the Blind	_____FIND, Inc. (CDP)	_____MN Deaf-Blind Technical Assistance Project
_____Your county social services	_____Duluth Lighthouse f/t Blind	_____RSC Equipment Distribution Programs
_____Other?_____	_____Parent Group, CLF	_____Other?_____

Would you like more information on what services these agencies provide? Please circle those you are interested in.

Comments:_____

3. What education professionals are you and your child currently working with? Are your child's needs being met? Please rate your satisfaction level by marking a number on a scale of 1-10 (1=unsatisfied, 10=completely satisfied.

_____Deaf/Hard of Hearing	_____DeafBlind Specialist	_____Occupational Therapist
_____Vision Teacher	_____Adaptive P.E. Spec.	_____Physical Therapist
_____O & M Teacher	_____Communication Specialist	_____1:1 Classroom Aide
_____Speech Therapist	_____1:1 Interpreter	_____E.C.S.E.
_____Other?_____		_____Other?_____

Would you like more information on what services these specialists provide? Please circle those you are interested in.

Comments:_____

4. Would you / your child benefit from having a DeafBlind specialist visit your home or school to provide training specific to your child? _____yes _____no

Comments:_____

5. Would you attend general DeafBlind training workshops outside your home (6 - 8 hours)? _____yes _____no

Comments:_____

(continued on back)

6. Does your child or your child's school recieve asssistance from the Deaf-Blind Technical Assistance Project?
_____Yes _____ No _____Don't know

Comments:_____

7. What medical professionals are currently serving your child? Are your child's needs being met? Please rate your satisfaction level by marking a number on a scale of 1-10 (1=unsatisfied, 10=completely satisfied).

_____Geneticist	_____Cardiologist	_____Pulmonologist	_____Dr. Sandra Davenport
_____Audiologist	_____Orthopedist	_____Endocrinologist	_____Developmental Pediatrician
_____Ocularist	_____Psychiatrist	_____Ophtholmologist	_____Ear, Nose, and Throat Spec.
_____Optometrist	_____Low-Vision Optometrist		_____Craniofacial Specialist

Would you like more information on what services these specialists provide? Please circle those you are interested in.

Comments:_____

9. Do you receive the free Parent Pages DeafBlind Newsletter_____yes _____no

10. If no, would you like to? _____yes _____no

11. If yes, has it been helpful _____yes _____no

12. How could it be improved to suit your needs?_____

_____

13. Are you interested in sharing information with other parents who have children with similiar issues?
_____yes _____no

Comments:_____

14. Are you interested in a parent group (i.e. "Children Linking Families") _____yes _____no

Comments:_____

15. If yes, how would you like to be involved? _____active organizer
_____participant

Comments:_____

16. Are you interested in a parent group specific to your child's diagnosis? ie. Meningitis, Stickler Syndrome, Usher Syndrome, CHARGE Syndrome, etc., etc. _____yes _____no
Comments:_____

17. If yes, how would you like to be involved? _____active organizer
_____participant

Comments:_____

18. Would you like to be involved in a Parent Advisory Committee to give direction to:
The Children's Discovery Project? _____yes _____no
State Services for the Blind? _____yes _____no
MN Deaf-Blind Technical Assistance Project? _____yes _____no

Comments:_____

19. Can we contact you if we have questions or information to share? _____yes _____no

Please note: the term "DeafBlind" includes a variety of vision and hearing losses.
Please include your name and address if you would like to share or receive information!

Minnesota State Services for the Blind Provides Resources for Children who are DeafBlind

by
Susan Shogren Smith

Minnesota State Services for the Blind is an excellent resource for children who are DeafBlind, and is in fact mandated to provide services to individuals who are DeafBlind. As the parent of a DeafBlind child, I have frequently been surprised at not only the services SSB can offer, but the organizations' flexibility in working with my son's teachers and me.

Before I go on, the following are some specific examples of items SSB has purchased for children who qualify for services:

- Advocacy (ie. attend IEP meetings)
- Low vision aides (magnifiers, monoculars, etc.)
- Vibrating pager system, for use within the home, to initiate communication
- Large print word processing program for a home computer to have continuity between home and school.
- Computer monitor stand to bring the monitor close to the child's face
- "Little Tykes" desk with built in light board to create necessary contrast
- Low vision exams
- Hammock so child can initiate his own movement
- Counseling and guidance

SSB's mission includes facilitating "the achievement of vocational and personal independence by children and adults who are blind or visually handicapped." To qualify for services, a child must have a vision loss that "creates an impediment to their vocational or personal independence." Once a child has been referred to SSB for assistance, the child will be assessed for eligibility and then, if the child qualifies, assigned a counselor. Children, 0-14, in the 9 county metro area will generally be assigned to Curt Johnson. Gwen Johnson, a transition counselor, would most likely be working with metro children ages 14-18. For children outstate, the SSB counselor would be from a regional office.

After being found eligible, based on the referral information, including reports from ophthalmologists and / or optometrists, and an audiologist, the counselor will develop a **Rehabilitation Plan** with the parents similar to an I.E.P., for the child. This plan outlines overall goals related to the vision loss. The counselor will often work with the child's vision teacher to identify needs.

Advocacy is often one of the most helpful resources SSB provides. The child's counselor will work closely with the parent to address concerns related to the child's vision. SSB can provide information, support to parents and referrals to appropriate professionals. Often, parents are interested in advocacy support within the school system. At the parents request, the SSB counselor may attend **I.E.P. Meetings.** The counselor can provide suggestions in ensuring the child's visual needs are being met within the school system.

(Continued on back side)

SSB Available to Assist Families with I.E.P.

(continued from front side)

In addition to advocacy, there are many other services through SSB, as long as these services are included as part of a **Rehabilitation Plan.** It may be possible for a child to receive **Adjustment to Blindness** services, **Independent Living skills Training** and / or **Compensatory Skills Training.** This becomes especially important as a child reaches transition age (14 years).

Assistive Technology Services including exploration of and training in Assistive Technology may be appropriate for some children. The child's SSB counselor can work with parents and teachers to examine whether or not there is assistive Technology with may help the child. This could possibly include communication boards or other devices not available through another source, such as Medical Assistance.

The services available through SSB vary depending upon each child's individual needs. Any parents having questions about a child's eligibility or whether specific services can be included in a care plan, should call either the child's counselor, or SSB at 642-0500/Voice or 642-0506/TTY. For outstate Minnesotans, call 1-800-652-9000 / Voice & TTY.

****

Curt Johnson Serves Children, 0-14, in the Metro Area

Many of the children served by the Children's Discovery Project also have Curt Johnson working as their Rehabilitation Counselor. Curt visits his client's homes, attends I.E.P. meetings, works with the children's teachers and troubleshoots with parents about the services and supports each particular child needs.

Many people are not aware of Curt's background and how he became involved with SSB. Curt grew up in Faribault, and had two brothers(one of whom is also legally blind) and two sisters. Curt had congenital cataracts which left him blind in one eye and having 20/400 vision in the other.

Curt attended school at the Minnesota State Academy for the Blind through graduation. Following graduation and three years of "bumming around" Curt completed Masseur Training. Curt worked at the YMCA in Winona as a Masseur while attending Winona State University, where he majored in Sociology and Psychology with a minor in History. Eventually, Curt went on to do Master's work in Rehab Counseling.

After attending Graduate School, Curt began working for Olmstead County DAC, which eventually led him to his current position as a career counselor at SSB.

In the winter, Curt organizes the "Ski for Life" program, which offers children who are blind or DeafBlind the opportunity to ski with the assistance of a volunteer. (Please call Curt if you are interested in having your child participate in this program!)

When not working, Curt enjoys spending time with his wife, whom he met in college, bike riding, reading historical fiction, listening to music, and cross country skiing.

FIRST RESPONDER COMMUNICATION AID

NO no

1 2 3 4 5 6 7 8 9 0

yes YES

WHITE BLACK BROWN RED ORANGE YELLOW GREEN BLUE

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

NO

NORTH

WEST EAST

SOUTH

I NEED	I AM
DOCTOR	OK
HELP	HURT
PROTECTION	SICK
TELEPHONE	LOST
DIRECTIONS	AFRAID
RIDE	ANGRY

I DON'T KNOW

I AM A CRIME VICTIM

I HAVE INFORMATION TO TELL

WHITE BLACK BROWN RED

CRAZY	I ME
GOOD BAD	MAN
FRONT BACK	WOMAN
NEW OLD	BOY
MANY FEW	GIRL
DARK LIGHT	BABY
IN OUT NEAR FAR	GROUP
BIG MEDIUM SMALL	ATTENDANT
PAST NOW FUTURE	ANIMAL

1 2 3 4 5 6 7 8 9 0

A B C D E F G H I K J K L

BLIND COMMUNICATION AID

ORANGE YELLOW GREEN BLUE

TAKE JACKET SHIRT PANTS

GO CAR TRUCK BUS

HEARD GUN KNIFE

SEE ALCOHOL DRUGS

TEASE MONEY PROPERTY

TOUCH HOUSE BUILDING

HIT NOISE DISTURBANCE

HURT FIRE ACCIDENT FIGHT

BREAK FOOD WATER

RAPE PRIVATE PARTS SEX

M N O P Q U V U W X Y Z

UP

LEFT RIGHT

DOWN

YES

I AM HERE TO HELP YOU

ARE YOU OK ?

DO YOU NEED A DOCTOR ?

DO OTHERS NEED HELP ?

WHAT HAPPENED ?

WHO CAN HELP ME TALK TO YOU ?

I NEED MORE INFORMATION

I DON'T UNDERSTAND - TRY AGAIN

WHO ? WHEN ? WHERE ?

HOW ? WHY ? HOW MANY ?

BEST COPY AVAILABLE

DISPLAY COPY

Guide to Services for Individuals with Deaf-Blindness

Some Recommended Guidelines for Individuals Planning, Developing and Implementing Service Choices for Families and Individuals with Deaf-Blindness

Joyce A. Surbeck
Editor

Developed by the
Advisory Council
to
the Minnesota Deaf-Blind
Technical Assistance Project

September 1994

The Advisory Council to the Minnesota Deaf-Blind Technical Assistance Project is a dedicated community of individuals who voluntarily gave their time to this activity. Any editorial comments are so noted; all materials contained herein are otherwise the direct work of the members of that council.

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Introduction

During the program year 1990-91, a topic of considerable importance for the Advisory Council to the Minnesota Deaf-Blind Technical Assistance Project was the seemingly randomness of services for individuals with deaf-blindness and their families. There appeared to be no standards for service provision even among those agencies which operated under either federal or state mandates to provide services.

Discussions centered around a functional definition which could be of practical use to all agencies and programs which provided services to individuals with deaf-blindness and/or their families. Minnesota was under a state mandate to provide entrance and exit criteria for all categorical programs in special education and the time seemed appropriate for these discussions to take on a more formal presence.

The first step in the process was to attempt to identify a common need of providers within the state of Minnesota. Membership on the Council consisted of representatives from state and private agencies and programs, consumers, families and advocates. All agreed that a common purpose among them was to assist and empower individuals and families toward an interdependent lifestyle in the community of his/her choosing.

Minnesota is, in many ways, a very homogeneous state with "pockets" of vast heterogeneity. It is also a geographically diverse state with few large urban areas. The largest metropolitan area is the Twin Cities area and the seven counties which make up this region. Most statewide services are administered from this area which not the geographic center of the state. The three major state agencies involved in direct service to individuals with deaf-blindness and their families are: the Minnesota Department of Education, Minnesota State Services for the Blind, and the Minnesota Department of Human Services and all are administered from St. Paul. Although all three of these agencies have regional offices, the regions are not always identical and regional office space are not always located in the same cities. As in most bureaucracies, regular and ongoing interagency planning was not the norm.

The Advisory Council saw itself as a potential model for interagency collaboration and the decision was made to assume a leadership role in the process of identification of guidelines for service provision throughout the state of Minnesota. There is a certain amount of wisdom in the idea that other states may learn from this experience and adopt, adapt, or reject certain elements which have been defined for Minnesota.

Upon discussion, the determination was made that providers working with individuals with deaf-blindness and their families in such areas as education, rehabilitation and transition need assistance with development of service choices. An exhaustive search of the literature was conducted to determine if there were guidelines or trends in service provision in the professional

literature. Although there were some very specific recommended approaches nothing was currently in print which could be discovered that met the needs of the Council.

Most of the material studied centered on a population with multiple disabilities; in particular, mental retardation. The question which was continuing to be asked was: What about the individual with Usher's Syndrome, CHARGE, RP and others which are not *necessarily* coupled with mental retardation?

Therefore, the Council embarked on a two-year project with the goal of developing this *Guide to Services for Individuals with Deaf-Blindness*. In an effort to offer easy access and readability, the *Guide* is divided into three sections. The first offers a functional definition of deaf-blindness and provides a comparison analysis of widely-used definitions. (*Editorial note: if other states are considering following this process, it would, perhaps, be beneficial to do a comparison analysis with your own state or agency recommended or required definition.)*

The second section identifies how services may be delivered to individuals with deaf-blindness and their families. Finally, the *Guide* lists some desired outcomes for students with deaf-blindness and offers a glossary in an effort to provide a common language between authors and readers.

At the close of the *Guide* the reader will find a User Satisfaction Form as well as methods by which additional copies may be ordered. We ask that you please honor the copyright procedures and adhere to bibliographic protocol.

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Dedication to a task such as this represents the high level of professional efforts and commitment of the participants. The following list represents the membership of the Advisory Council at the time this activity was begun and then studied. Very grateful appreciation goes to the following:

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Introduction 2

I. Definitions

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A Service-Directed Definition as developed by The Advisory Council to the MN Deaf-Blind Technical Assistance Project

Deaf-blindness means any combination of vision and hearing loss which interferes with acquiring information from the environment to the extent that compensatory strategies and skills are necessary to access that or other information.

Deafness interferes with oral/aural communication and auditory environmental cues, whereas blindness limits visual communication (sign language, print, etc.) and visual environmental cues. together, they limit the amount of information a person can gain from the environment: i.e., from people, objects, motion, or other cues. Changes in the environment, such as lighting or noise, may also have a significant impact on a person's ability to use residual vision or hearing.

No two individuals with deaf-blindness have the same combination of vision and hearing loss unless they are totally deaf and blind. Even then, one may have been born deaf and become blind, another born blind and become deaf. A third may have lost vision and hearing at an early age, and another may have been born deaf, blind, and mentally impaired.

Those with partial vision and hearing also arrive at this state from different backgrounds. An individual may lose or even gain vision or hearing over time. Needs vary significantly and any definition of deaf-blindness must accommodate medical and functional aspects of this dual sensory loss.

The concept of "at risk" or "at risk-ness" is not explicitly included or excluded in the above definition. We are all at risk for illness or injuries that lead to or may lead to deaf-blindness. However, certain conditions like Usher Syndrome include the risk of deaf-blindness by definition since individuals with Usher Syndrome steadily lost their vision because of retinitis pigmentosa.

The above definition is the result of an evolutionary process over many, many hours of spirited discussions. The emphasis is place on the needs of the individual and not the requirements of a perceived agency or program. The locus of control is place with the individual, if feasible. At the same time, this definition provides agencies and programs with a base from which to develop a definition that conforms to rules and regulations from which they must operate and function.

Other widely-used definitions are listed on the following pages. *Figure 1* compares the elements of these definitions.

Minnesota Department of Education Rule 3525.1327

DEAF-BLINDNESS

In the format of the revisor..

Subpart 1. **Definition and criteria.** "Deaf-blindness" means medically verified visual impairment coupled with medically verified hearing impairment that, together, interfere with acquiring information or interacting in the environment. Both conditions need to be present simultaneously and must meet the criteria for both vision and hearing impairments.

Subpart 2. **Pupils at risk.** Pupils at risk for deaf-blindness include, but are not limited to:

A. those that are already identified as hearing or vision impaired and have not yet had medical or functional assessment of the other sense (vision or hearing);

B. have an identified syndrome, such as Usher Syndrome or Rubella Syndrome, that includes a potential deterioration of vision or hearing in the future;

C. those that have a medically or functionally identified hearing impairment and a verified deficit in vision determined by a functional assessment in the learning environment; and

D. those that have a medically or functionally identified vision impairment and verified deficit in hearing determined by a functional assessment in the learning environment.

3525.1331 HEARING IMPAIRMENT

Subpart 1. **Definition.** "Hearing impairment" means a diminished sensitivity to sound that is expressed in terms of standard audiological measures.

Hearing impairment has the potential to affect educational, communicative, or social functioning that may result in the need for special education instruction and related services.

Subpart 2. **Criteria.** The team shall determine that a pupil who has a hearing impairment is eligible for special education instruction and related services if the pupil meets one of the criteria in item A and one of the criteria in item B, C, or D.

A. There is audiological documentation provided by a certified audiologist that verifies one of the following:

(1) a sensorineural hearing loss with an unaided pure tone average, speech threshold, or auditory brainstem response threshold of 20 decibels hearing level (HL) or greater in the better ear;

(2) a conductive hearing loss with an unaided pure tone average or speech threshold of 20 decibels hearing level (HL) or greater in the better ear persisting over three months as verified by audiograms with at least one measure provided by a certified audiologist;

(3) a unilateral sensorineural or persistent conductive loss with an unaided pure tone average or speech threshold of 45 decibels hearing level (HL) or greater in the affected ear; or

(4) a sensorineural hearing loss with unaided pure tone thresholds at 35 decibels hearing level (HL) or greater at two or more adjacent frequencies (500 hertz, 1000 hertz, 2000 hertz, or 4000 hertz) in the better ear.

B. The pupil's hearing impairment affects educational performance as demonstrated by:

(1) a need to consistently use amplification appropriately in educational settings as determined by audiological measures and systematic observation; or

(2) an achievement deficit in one or more of the following that is at the 15th percentile or 1.0 standard deviations or more below the mean on a technically adequate norm-referenced achievement test that is individually administered by a licensed professional:

(a) basic reading skills;

(b) reading comprehension; or

(c) written language.

C. The pupil's hearing impairment affects the use and understanding of spoken English as documented by one or both of the following:

(1) under the pupil's typical classroom condition, the pupil's classroom interaction is limited as measured by systematic observation of communication behaviors; or

(2) the pupil uses American sign language or one or more alternative or augmentative systems of communication alone or in combination with spoken English as documented by parent or teacher reports and language sampling conducted by a knowledgeable professional.

D. The pupil's hearing impairment affects the adaptive behavior required for age-appropriate social functioning as supported by:

(1) documented systematic observation within the pupil's primary learning environments by a licensed professional and the pupil, when appropriate; and

(2) scores on a standardized scale of social skill development are below the average scores expected of same-age peers.

3525.1345 VISUALLY IMPAIRED.

Subpart 1. **Definition.** "Visually impaired" means a medically verified visual impairment accompanied by limitations in sight that interfere with acquiring information or interaction with the environment to the extent that special education instruction and related services may be needed.

Subpart 2. **Criteria.** The team shall determine that a pupil is eligible as having a visual disability and in need of special education if the pupil meets one of the criteria in item A and one of the criteria in item B.

A. There is medical documentation of a diagnosed visual impairment by a licensed eye specialist establishing one or more of the following conditions:

(1) visual acuity of 20/60 or less in the better eye with the best conventional correction; estimation of acuity is acceptable for difficult-to-test learners;

(2) visual field of 20 degrees or less, or bilateral scotomas; or

(3) a congenital or degenerating eye condition including, but not limited to, progressive cataract, glaucoma, retinitis pigmentosa, albinism, or nystagmus.

B. A functional assessment of visual abilities conducted by a licensed teacher of the visually disabled determines that:

(1) the pupil has limited ability in visually accessing program-appropriate educational media including, but not limited to, textbooks, photocopies, ditto copies, chalkboards, computers, or environmental sign, without modification;

(2) the pupil has limited ability to visually access the full range of program-appropriate educational materials and media without accommodating actions including, but not limited to, changes in posture, body movement, focal distance, or squinting;

(3) the pupil demonstrates variable visual ability due to environmental factors including, but not limited to, lighting, contract, weather, color, or movement, that cannot be controlled; and

(4) the pupil experiences reduced ability due to visual fatigue.

Minnesota State Services for the Blind

"Deafness" is a physiological chronic hearing impairment so severe that most speech cannot be understood through the ear with optimum amplification. The speech discrimination score should be 40 percent or less in the better ear.

"Visual Disability" means visual acuity does not exceed 20/60 in the better eye with corrective lenses. Visual acuity may be greater than 20/60 if the field of vision is constricted to 20 degrees or less. "Blindness" means visual acuity does not exceed 20/200 in the better eye with corrective lenses.

Federal - Public Law 98-199

"Deaf-blind" means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational problems that they cannot be accommodated in special education programs solely for deaf or blind children.

"Hard of hearing" means a hearing impairment, whether permanent or fluctuation, which adversely affects a child's educational performance but which is not included under the definition of "deaf".

"Deaf" means a hearing impairment which is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, which adversely affects educational performance.

"Visually handicapped" means a visual impairment which, even with correction, adversely affects a child's educational performance. The term includes both partially seeing and blind children.

For a definition of "Blind", refer to the MN State rule.

Gallaudet University

"Hearing impairment" means a hearing disability ranging in severity from "mild' to "profound". The severity of impairment is measured in decibels - the loudness or intensity required for a sound to be heard. The term "hearing impaired" includes people who are hard of hearing as well as those who are deaf. Individuals who are hard of hearing generally have some residual hearing that may enable them to understand speech and use the telephone with the help of a hearing aid (amplification) or other assistive device. An individual whose loss is at the most severe end of the spectrum is referred to as deaf and is unable to hear and understand speech even with amplification. People who are not familiar with various types of hearing loss may refer to a hearing impaired individual as deaf and assume that he or she is unable to hear at all, even though the person may have some residual hearing and a less severe loss.

Visual impairments also vary in severity. "Legal blindness" is defined as the inability to see at a distance of 20 feet what someone with normal sight can see at a distance of 200 feet, or peripheral vision that is restricted to 20 degrees or less (tunnel vision).

Nordic

A person is deaf-blind when he/she has a severe degree of combined visual and auditory impairment. Some deaf-blind people are totally deaf and blind, while others have residual hearing and residual vision. The severity of the combined visual and auditory impairments means that deaf-blind people cannot automatically utilize services for people with visual impairments or with hearing impairments. This deaf-blindness entails extreme difficulties with regard to education, training, working life, social life, cultural activities, and information.

For those who are born deaf-blind, or who acquire deaf-blindness at an early age, the situation is complicated by the fact that they have additional problems affecting their personality and behavior. Such complications further reduce their chances of exploiting their residual vision or hearing.

Deaf-blindness must therefore be regarded as a separate disability which requires special methods of communication and special methods for coping with the functions of everyday life.

Comparison of Definitions of Deaf-Blindness Figure 1

	Advisory Council	MN Dept. of Ed.	MN State Services for the Blind	Gallaudet University	Federal Public Law 98-199	Nordic
Requires a medically verified visual impairment		✓	✓			
Requires a medically verified hearing impairment		✓				
Both conditions must be present	✓	✓			✓	✓
The impairments interfere with acquiring information	✓	✓				✓
The impairments interfere with interacting in the environment	✓	✓				✓
The impairments cause severe communication and other developmental and educational problems		✓			✓	

	Advisory Council	MN Dept. of Ed.	MN State Services for the Blind	Federal Public Law 98-199	Gallaudet Univer-sity	Nordic
Additional problems if individual is born deaf-blind or if acquired at an early age						✓
Regard deaf-blindness as a separate disability	✓	✓	✓	✓	✓	✓
Children at risk include those identified with one impairment but not medically assessed for the other		✓				
Children at risk may not yet be medically assessed for visual or hearing impairment	✓	✓				
Children at risk include those with an identified syndrome with a potential deterioration	✓	✓				
Functional hearing impairment defined		✓		✓		
Hearing impairment means need for some type of amplification		✓		✓		
Hearing impaired means achievement deficit		✓		✓		

	Advisory Council	MN Department of Education	MN State Services for the Blind	Federal Public Law 98-199	Gallaudet University	Nordic
Hearing impairment affects social skill development		✓				
Medical hearing impairment defined		✓	✓		✓	
Medical hearing impairment means sensorineural hearing loss (20dB or greater)		✓				
Medical hearing impairment means conductive hearing loss (20dB or greater)		✓				
Medical hearing impairment means unilateral sensorineural or persistent conductive loss (45dB or greater)		✓				
Medical hearing impairment means sensorineural hearing loss at two or more adjacent frequencies (45dB or higher)		✓ (40dB+)				
Deafness means the speech discrimination score should be 40% or less in the better ear			✓			
Functional visual handicap defined				✓		

Visual handicap means limited ability to access educational media		✓		✓		
	Advisory Council	MN Department of Education	MN State Services for the Blind	Federal Public Law 98-199	Gallaudet University	Nordic
Visual handicap means accommodating actions necessary to access educational materials		✓				
Visual handicap means variable visual ability due to environmental factors		✓				
Visual handicap means variable visual ability due to fatigue or conditions idiosyncratic to the eye condition		✓ ("visual fatigue" only)				
Visual disability means meeting specific criteria		✓	✓			
Visual impairment requires medical documentation establishing the condition		✓	✓			
Visual impairment may be determined by way of a functional assessment		✓				
Blindness means visual acuity that does not exceed 20/200 in the better eye with corrective lenses, or a field of vision constricted to 20 degrees or less			✓		✓	
Hearing impairment affects use of spoken English		✓				

Figure 1 concluded

II Service Delivery

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"There is no question that the dual disability of deafness and blindness is one of the severest handicaps known to mankind, and that people who lose both sight and hearing face unique problems that make it difficult for them to function independently. Sight and hearing are the primary channels through which we acquire information and knowledge of the world we live in; and when these two senses are damaged or absent, there are serious problems of communication, orientation, and mobility that limit the deaf-blind individual's sense of independence."

Robert J. Smithdas
(from a keynote address to the 4th Helen Keller World Conference, 1989, Stockholm, Sweden)

Editorial note: this section is intended to provide an explanation of service delivery as a system. In other words, the client/consumer/indivdiual with deaf-blindness is at the center of the system and wrapped around that individual is his/her family and community as she/he defines them. Interrelated and interdependent subsystems surround this core. In systems theory and practice, some impact on one subsystem affects all of the other subsystems in either a direct or indirect way. It would behoove any organization to plan the delivery of service in a systems fashion so that some interrelationship or interdependence is not overlooked. An interrelationship or interdependence can manifest itself as a contingency to accomplishing the desired outcome. It is essentially impossible to accurately identify all possible interrelationships and interdependencies, but an attempt to bring them into the planning process brings them into the planning "consciousness".

Subsystems will be quite different from state to state and even from community to community. Agencies and programs are different just as individuals are different. Unless the planners give thought to who/what ought to be involved in the service system, the desired outcome could remain as a "what if" instead of a "what can be" or a "what is".

(Please refer to the glossary for specific definitions as determined by the Advisory Council Subgroups for this document.)

Editorial note: the Advisory council gave considerable thought and discussion to the differences between interdependence and independence. The conclusion was made that the ultimate for any citizen is to reach interdependence, working together with others to reach a common outcome. However, an individual must first be independent in that skill BEFORE she/he can work with someone else to reach it. Interdependence conceptually refers to the development and forming of communities.

The Advisory Council membership determined to first examine what interdependence and community building meant to each of them as an individual. Since the vast majority of that membership are themselves, temporarily able-bodied, it is impossible to move themselves into

the heart and mind of someone with deaf-blindness. There was an individual with deaf-blindness on each of the working subgroups and their input and forthright discussions were extremely valuable, the decision was made to consider first and foremost, that an individual with deaf-blindness is first an individual and the disabling conditions are secondarily or tertiary to the individual.

Keeping that in mind, interdependence was determined to be a higher value than independence. We as professionals, families and advocates attempt to understand the isolation that accompanies deaf-blindness. The very word: independence, connotes aloneness, solely involved.

A second value which was determined to be necessary for appropriate service delivery was that of community-membership. The definition of community as developed by the Foundation for Community Encouragement seems to be the most appropriate for this discussion: Community is best defined as a group of two or more people who regardless of the diversity of their backgrounds have been able to accept and to transcend their differences, enabling them to communicate effectively and to work openly together towards goals that serve their common good.

The individual has the right to choose what his/her community should be and ought to be taught how to develop his/her own community of friends and associates. With that philosophy in mind, the workgroup developed the following material on service delivery.

Interdependence for the individual with deaf-blindness requires the coordination of several factors in four key areas: identification, accessibility, support services, and policy. The task the Advisory Council was to identify how service is currently being delivered to individuals with deaf-blindness in these four areas:

- **Identification** - the determination of an individual's ability to receive and process auditory and visual stimuli.
- **Accessibility** - assessments, planning, training, socialization, and transportation that will enable the individual with deaf-blindness to learn, grow, and achieve a sense of independence.
- **Support Services** - those services identified as appropriate to enhance independent living skills, employment skills, leisure/recreation, and community integration.
- **Policy** - the use of the legislative system to communicate and promote issues concerning deaf-blindness and the use of the legal system to enforce laws that affect individuals with deaf-blindness.

IDENTIFICATION

The identification of deaf-blindness, of diseases that can cause deaf-blindness, of degenerative conditions that can lead to deaf-blindness, and of conditions that require assistance can occur before birth and throughout a person's life. Figure 2 lists when identification can occur and the provider of this identification service.

Figure 2: When Identification Can Occur

Age	Service	Provider
Prenatal	❑ Amniocentesis/prenatal diagnosis	Obstetrician/geneticist
	❑ Invitro surgery	Physician
Birth	❑ Apgar evaluation at birth and five minutes after birth	Physician
	❑ Low Apgar score may lead to medical tests	Physician
	❑ Referral to well baby clinics for low income families, teenage mothers, premature or stressful births, or low birth weights	Nurse
Birth - Age 21	❑ Children's Home Care Options	MN Department of Human Services
Birth to Death	❑ Hearing Screening	MN State Services for the Blind (any consumer with vision impairment must be referred for hearing screening in MN)
Infant	❑ Periodic Health Check-Ups	Physician, public clinic, State Services for the Blind, & MN Department of Education Rules for Public Schools
Preschool	❑ Vision & Hearing Tests	Public schools, Public Health
	❑ Pediatric check-ups	Physician
	❑ Health Fairs	MN Department of Public Health

Kindergarten - 12th Grade	❑ Annual vision/hearing screening	Public schools, MN Department of Public Health
Ages 14-21	❑ Reassessment for eligibility	State Services for the Blind
Age 18	❑ Eligibility for financial services	Legally an adult
Adult	❑ Functional assessments as needed for activities of daily living (ADL), adaptive kitchen skills (AKS), orientation and mobility (O&M), communication skills, money management, social/recreational, mental health counseling, peer support, and/or family support	MN State Services for the Blind
	❑ Employer input/training	Employer (ADA & 504)
	❑ Financial assistance (Supplemental Security Income/ Social Security Disability Insurance, medical assistance, Medicare, Medicaid, retirement funds, trust funds, etc.)	Employer, Social Security Administration, Medicare, Medicaid, private insurers, State Services for the Blind

Figure 2 concluded

ACCESSIBILITY

Promoting accessibility to services begins when a child is an infant and toddler. Early childhood special education programs along with taking advantage of specialized day care options, WIC programs, and other public health programming, can help parents explore all possible channels of communication with their child, including visual and tactile methods. To empower individuals and families to make informed choices, it becomes critical to present the information in the most appropriate, useful, and understandable ways and channels.

Early communication and information sharing goals and objectives are addressed in the goal-setting document required of Birth-2 programs in special education, the Individual Family Service Plan (IFSP). The intent of this plan is to identify steps which should be taken to provide the greatest amount of support to the infant and toddler by way of support to the family. A family needs assessment is conducted which, of course, includes specific information regarding the child. Identified needs are used as the basis for goal-setting and may include such services as: respite care services, specialized day care, communication training for siblings and parents and/or parenting individuals, linkages with other agency service providers, and systematic exposure to and involvement in the community and its resources. The need for a comprehensive evaluation and ongoing reevaluations may be a principle consideration at all ages.

Editorial Note:
One example from the education system is that of the Individual Education Plan or IEP. The plan is developed upon the entry of a child with specialized education needs anywhere between the ages of 3 years and graduation from high school or age 22. The plan is written for a twelve-month calendar period and is developed and evaluated by a team of individuals. The parent and/or parenting individuals and the child, when considered appropriate, are equal participants with school professionals and others as meets the needs of the individual child. The purpose of the IEP is to identify present levels of performance in academic areas as well as social and emotional functioning. In each of these area, a statement of need for specialized services is developed. A child does not need to have a so-called "deficit" in all of the present level of performance areas to receive specialized services. Indeed, the determination for specialized services is the final decision made by the team after all of the IEP form is completed.

There may or may not be a statement of need for each of the present levels of performance areas. However, it is highly likely, that a goal statement will be written for each statement of need. Sometimes, for very young children who are challenged with multiple conditions which are disabling, the needs will be prioritized by the team (again, the family must be provided the opportunity to participate on that team; however, if the family chooses not to participate, the school is obligated to continue without their direct input) and goals which are the most developmentaly-appropriate would likely to be pursued first.

For a child with deaf-blindness some educational strategies might be: the development of skills in English as a second language for a child whose first language is American Sign Language, an emphasis on functional communication skills, or the development of a functional curriculum.

As the individual progresses through formal schooling, he or she should have access to information about recreation and leisure opportunities in the community. Information on sexual development and personal sexuality is also important to the developing youngster. Socialization information and skill training along with job skill techniques and strategies and independent living skills are just as important for the youth with deaf-blindness as they are for the so-called "typical" adolescent. The accommodations and methodologies may appear quite differently, the basic goals may very well be identical.

Therefore, the development of educational objectives, the next step in the IEP development process, is so crucial. The objectives tell the service provider where the training will occur, what materials are to be used, with whom the training will occur, the circumstances or conditions under which the trianing/desired behavior will occur/develop, and the degree or rate of satisfaction/criteria that will be acceptable at the individual child's developmental level in order to determine if learning has occurred.

A very important part of the IEP is the portion that deals with what is known as the LRE statement or least restrictive environment. It is here that the discussion occurs about whether the needs as outlined earlier can be met in the regular classroom without specialized interventions. If the answer is "no", then a reasonable justification must be written into the plan. If the answer is "yes", then, of course, the child remains in the regular classroom.

If, however, the individual child's needs not the needs of the district, not budgetary needs and so on, are such that the child needs supplemental support, then the team (again, with the family's input) determines the type of support he or she needs in order to make progress. Remember: the IEP is not a guarantee for success. It is, however, a service agreement. Many people make the mistake by assuming that the level of achievement or growth as outlined in the objectives section MUST be met by the school. That is a false assumption.

Consider, if you will, the myriad of variables that exist in any learning environment. It is impossible to plan and meet all of those variables with any rate of accuracy. Therefore, the criterion portion of the education objectives remain as an end to which the team aspires for the individual child. In other words, they are the target, and with all things being equal and all variables controlled (which cannot occur), they will be reached. In an ideal world, all children would meet all objectives to all goals annually. Practically, that just cannot occur. It is true that goals and objectives could, in fact, be written in such a manner that the child would attain them ALL. In like manner, goals and objectives could be written in such a manner that the child would NEVER attain a one. The input of the family and significant others is so vital to the total picture of the child and the child's world that emphasis cannot be expressed too strongly on this point.

Next, what type of service intervention or interventions would better enable the child to function in the general education environment. These are to discussed and considered based on the need statements previously developed for this individual child, not based upon what is available currently in that child's school or district. It is a "dream" statement, if you will about what should be, not what is. Reasonableness must be present in this discussion, according to the law,

and families and advocates should keep that in mind. A rule of thumb might be to ask: "What have we tried, what worked and why? What have we overlooked and could that be a benefit to the child?"

Lastly, after all the considerations have been given to present levels of performance, statements of need, goals and objectives, participation in the regular education program and the type of educational support or supports needs, is the decision to place a child in special education. This is the last decision in the process for very good reasons:

- *placement also means labeling and labeling, in today's society, frequently carries negative stigma;*
- *all considerations must be given to whether, or to what degree, the child can remain in the regular education environment;*
- *posing and answering the questions about other agencies and programs which might be available and beneficial to the process;*
- *some assurances that the parents and/or parenting individuals have had the opportunity to provide input and ask questions about the education program the child is currently enrolled and future programming options and opportunities; and,*
- *fully exploring the service NEEDS of the child above the needs of the system or other individuals.*

An area of particular concern to individuals with deaf-blindness is accessibility to public transportation. This means full enforcement of accessibility codes and regulations, appropriate representation of the deaf-blind on the Regional Transportation Board, communication with the Department of Transportation and Federal Aviation Agency, and equal access to Orientation and Mobility services.

SUPPORT SERVICES

To provide the appropriate services to individuals with deaf-blindness and their families, the following support services are recommended:

- **Family/Consumer**
  The development and implementation of an ongoing case management or coordination system. The case manager ought to be selected according to the primary need of the family or consumer.
- **Advocacy Information**
  The provision of advocacy information is a lifelong process. The process includes identifying all advocacy agencies and services, making sure a full array of services are provided using methods of communication appropriate for consumers, recognizing the needs of both the consumer and the agency providing those services (such as a hospital), and providing specialized in-service training for people in such roles.
- **Respite Care**
  A statewide respite care program for families and individual would be extremely beneficial in providing care on a sliding fee scale, staffed by people with communication skills that match the needs of the individual, and accessible 24-hours a day with minimal lead time. The program would serve all age and income ranges and levels.

- **Emergency Care**
  Support services in this area focus on ensuring proper emergency care for individuals with deaf-blindness. This includes training of emergency personnel, providing the appropriate mode of communication for the individual, establishing 911 TTY as direct two-way communication, developing and disseminating a list of emergency interpreters, and exploring alternative methods of emergency identification chosen by the individual.
- **Mental Health**
  Mental health service providers must be located who can and will work wit consumers with deaf-blindness and their families. This process includes increasing awareness of the unique needs of consumers through in-service and college training, identifying gaps in service (such as mental health professionals who are unable to communicate with individuals with deaf-blindness), and developing incentives for accepting consumers (such as bonus proficiency pay and smaller caseloads).
- **Legal Services**
  As with mental health services, legal professionals must be identified who will work with consumers to inform them of their legal rights and adequately and professionally represent individuals with deaf-blindness and their families. Training for these professionals, both law school and in-service training, should be developed to communicate the unique needs of consumers.

POLICY

Legislative Issues

To have an impact on legislation that affects consumers and their families, people must be involved in the legislative process from the initiation of a bill to the enactment into law and ongoing interpretation of that bill. Opportunities for involvement in this process may include some of the following:

- contribute public testimony
- involvement in community action
- involvement in appropriate public and private agencies and coalitions
- identify key legislators at the state and federal levels who are willing to author bills
- identify state and federal agencies that would manage a new project or program
- identify precedents that support new initiatives
- identify key congressional committees that will discuss the bill
- communicate with the National Deaf-Blind Coalition
- educate community members with deaf-blindness about legislative issues

Legal Issues

It is important to review compliance with and pursue enforcement of all applicable federal, state, and local laws concerning the rights of individuals with disabilities in such areas as: employment, education, health care, housing, communication, transportation, insurance, and benefits.

Assistance in each of these four areas is available through state service providers. For a listing of providers, refer to the Resource Guide for People in Minnesota with Vision and Hearing Loss, Vision Screening Project, Sandra L.H. Davenport, M.D., Director, 1994., which is included at the end of this document.

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III. Outcomes

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The third task of the Advisory Council was to identify what students with deaf-blindness should know and be able to do as a result of elementary and secondary education programming. The results of that effort are shown on Figure 3 at the close of this section.

During the research and discussions that produced these outcomes, the Council recognized that certain key issues must be addressed for the desired results to be achieved. We present those issues here in the hope that they will outline the Council's thinking on this matter while stimulating further discussions among individuals with deaf-blindness, their parents and families, and those who provide services to them.

To achieve the desired outcomes for individuals with deaf-blindness, we believe there is a need for:

1. Greater cooperation among individuals with deaf-blindness, their families and siblings, school district staff (administrators, teachers, related service providers), lawmakers, health professionals, community service providers, and rehabilitation counselors.
   - ► A stronger collaboration effort among these groups must be established throughout the individual's lifelong learning process. The purpose of the collaboration is to give individuals with deaf-blindness opportunities for more positive and consistent social, educational, and vocational experiences.
   - ► Leaders must be committed to working toward improving the lives of individuals with deaf-blindness. With the State Legislature's assistance, creative funding could be established to develop programs. Those involved in the educational process should be challenged to focus on developing the "whole" individual, which includes academic accomplishments and socialization that will enhance their ability to lead productive and fulfilling lives.
   - ► Society must re-focus its values and belief systems so that they more fully support and nurture the growth of self-esteem for individuals with deaf-blindness.
   - ► Families of individuals with deaf-blindness, educators and other professionals, and persons with disabilities must collaborate to produce appropriate early intervention services, accurate assessment and identification, and sharing of diagnoses with families in a sharing and humanistic manner. Continued collaboration will help the entire family and support network adjust while offering families a full continuum of educational, social, and vocational options, all of which encourage informed choices leading to empowerment and self-advocacy.

2. Expanded outreach activities to sensitize and train the public about deaf-blindness.
   - ► Outreach programs must be developed that focus on the individual as a person with unique strengths, positive qualities, areas of need, and above all, dreams for the future. These programs should dispel misconceptions, misunderstandings, and fears of deaf-blindness and create an awareness and

sensitivity toward the psychosocial aspects of deaf-blindness, which will help prevent isolation and discrimination.

- ► Outreach activities need to occur at al levels of public, private, and community education. Opportunities for networking need to occur in a planned manner among all concerned about deaf-blindness, including educators, health care professionals, community service providers, emergency care providers, day care providers, therapists, lawmakers, parents, and family members.
- ► Increased public awareness will mean greater public acceptance of individuals with deaf-blindness and their families, and an increased sense of self-worth for those individuals. to increase public awareness there must be ongoing media coverage about deaf-blindness, individuals with deaf-blindness, and the deaf-blind community.

3. Individuals with deaf-blindness to serve as positive role models in their communities, especially in the educational and service provider systems.
   - ► Individuals with deaf-blindness who demonstrate leadership skills should be encouraged to help raise awareness for educators, service professionals, their peers, and others. These leaders must then be integrated into the society at large and work force to provide children and youth with vital adult role models who are productive and valued. This exposure will give all children and youth, not just those with deaf-blindness, the opportunity to learn the unique challenges associated with this disability and to interact with, build respect for, and accept the individual as a valuable person.

4. Support groups that enable children and youth with deaf-blindness, families of individuals with deaf-blindness, and adults with deaf-blindness to network with others.
   - ► Many of the unique needs of individuals with deaf-blindness and their families can be met through support groups. By using the tool, networking, the families and individuals can help each other solve everyday difficulties and imagine and create a future that makes it possible for people with deaf-blindness to live productive and meaningful lives.

All people concerned about individuals with deaf-blindness are challenged to help meet their needs and develop their full potential as contributing members of society. It has been demonstrated that individuals with disabilities can make a better world with a common focus and a common dream that all people will enjoy positive and challenging lives as a result of the best possible education. Individuals with deaf-blindness are no exception.

Figure 3

Criteria for Students with Deaf-Blindness

Upon Exiting the Educational System (0-22)

Knowledge	Skills
Academic ☑ In addition to instructions and related services necessary to lessen the effect of or overcome barriers to learning posed by disabling condition(s), students with deaf-blindness should receive the same educational opportunities and be subjected to the same measures of anticipated learner outcomes as those who are not deaf-blind.	**Learning** ☒ Lifelong problem-solving skills in areas of personal expansion
Career Choices ☑ Be aware of the full range of jobs available ☑ Obtain knowledge of the educational requirements of the job ☑ Be aware of career ladders associated with a career choice ☑ Work with vocational counselors ☑ Be apprised of the compensation package at the work place and develop awareness of the relationship between benefits and lifestyle choices	**Employment** ☒ Develop a purposeful relationship with the vocational counselor ☒ Develop writing skills ☒ Develop interview skills ☒ Develop job retention skills such as, punctuality, dependability, and ability to follow others
Transportation Modes ☑ Have knowledge of public transportation (specialized transit system) ☑ Know the criteria for selecting the most appropriate mode of transportation for the circumstances	**Mobility** Each individual should be able to travel independently with such skills as: ☒ Traveling with a cane ☒ Sighted-guide techniques ☒ Moving about in a familiar environment independently or with cane/guide-dog ☒ Ability to use the commercial transportation system ☒ Demonstrate the ability to use

Figure 3 continued

Avocation, Leisure/Recreational, Health and Fitness

☑ Have knowledge of hobbies and handicrafts

☑ Identify location of recreational sites

☑ Learn the rules for a variety of recreational activities

☑ Have knowledge of own disabling conditions

☑ Adopt healthy exercise and eating habits to deter disease and live a long and satisfying life

☑ Obtain knowledge of the health and care systems

☑ Obtain knowledge of symptoms, treatment and implications of common illness

Avocation, Leisure/Recreational, Health and Fitness

☒ Develop abilities for physical fitness activities

☒ Develop abilities to fully participate in a wide range of recreational and leisure activities

☒ Operate communicate devices

☒ Express symptoms of disabling condition

Figure 3 continued

Communications (Resources & Operations)

☑ Each individual should have full knowledge of communication modalities for use in appropriate circumstance, such as:

1. Speech-Lipreading
2. Sign language
   - Signed English
   - Finger spelling
   - Print-on-palm
   - American Sign Language
     - tactile
     - visual
3. Braille
4. Writing
5. Typing
6. Use telephone relay systems
7. Assistive devices and technologies (including, but not limited to, computers, magnifiers, closed-cpation television, hearing aids, and TTY)

☑ Obtain knowledge of communications and media devices available to communicate information, such as newspapers, radio, and electronic bulletin boards

☑ Know how and where to access interpreters and how to use them effectively

☑ Gain knowledge of local, state, and federal agencies that provide communication services/devices such as materials in Braille, reader services, communication equipment, and Braille transcription services.

Communication

☒ Develop proficiency in all types of communication modalities available

☒ Ability to access timely information from current world, regional, state, and local events

☒ Ability to communicate, as desired, with peers, especially typical peers

☒ Demonstrate the ability to work with interpreters of differing skill levels

Figure 3 continued

Socialization Process

☑ With the assistance of counselors, develop self-acceptance through interaction with peers and others who are non-disabled, in educational and social settings

☑ Develop positive interaction with deaf-blind role models who have serve as counselors or instructors in the educational system, i.e., have had the opportunity to learn that it is okay to be deaf-blind and that a person can be productive and valuable to society regardless of disabling conditions or the degree of those conditions

☑ Develop positive family interactions

☑ Have knowledge of resource to locate goods and services

Socialization

☒ Develop independent living skills such as:

1. Basic self-care (bathing, dressing, eating, grooming, toileting)
2. Food (nutrition, purchasing, preparation)
3. Safety (self-defense) - the capacity to respond to emergency situations such as those caused by illness, injury, threat to personal safety, or change in the environment, i.e., fire, weather, abuse issues
4. Laundry, housekeeping
5. Money management
6. Physical fitness
7. Assertiveness training
   - self-esteem issues
   - decision-making
8. Explore recreation/leisure options (develop hobbies)
9. Sex education and sexual identity (including abuse issues)
10. Socialization
    - appropriate behavior
    - making and keeping friends
    - trust versus untrustworthiness

Figure 3 concluded

Resource Guide

Refer to the Resource Guide for People in Minnesota with Vision and Hearing Loss, Vision Screening Project, Sandra L.H. Davenport, M.D., 1994.

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Glossary

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Accessibility - the provision of services, including assessments, planning, training, socialization, and transportation, that will enable he individual with deaf-blindness to achieve learn, grow, and achieve a sense of independence.

Assessment - collection of information for determining appropriate intervention.

Career - an individual's choice(s) for life work.

Collaboration - two or more individuals, agencies, teams, programs, or systems working together in a non-dichotamus process to develop an alternative or alternatives which benefit all concerned.

Community - a group of two or more people who regardless of the diversity o their backgrounds have been able to accept and to transcend their differences, enabling them to communicate effectively and to work openly together toward goals that serve their common good.

Developmentally-Appropriate Education - an education methodology that consists of two aspects: age appropriateness and individual appropriateness; which encompass multidimensional (e.g., multiple domains) opportunities for learning for the "whole" child and do not necessarily occur in a linear order or in chronological sequence.

Evaluation - a measurement of change from point "a" to some point "n".

Family - a basic social unit in which a child or youth feels a sense of belonging.

Functional Skills - those competencies required to operate in a given environment.

Goals - must be developed and included in each individuals' Individualized Education Program (IEP) who received special education services within a public school program. Goals must be developed from the statement of need of service which are derived from present levels of performance that have been generated from a variety of assessment sources. Goals are typically global in nature; however, they should be clearly articulated and narrow enough that the language is actually observable and measurable. The US Supreme Court has stated through opinion, that although goals are to be written into the IEP for 12 calendar months at maximum, the team must always consider the future of the pupil beyond formal, public education. In other words, goals should be authentic for the individual even if she/he is in the first grade; reasonableness and realistic future goals may be a genuine look at independent living upon completion of twelfth grade, therefore, goals should be functional in nature.

Identification - the determination of an individual's ability to receive and process auditory and visual stimuli.

Individualized Education Program (IEP) - Often mistaken for Individualized Education Plan, the IEP was intended by Congress to be a dynamic, active, ongoing program, not merely a plan on paper. Unfortunately, all too often these "dynamic" programs are nothing more than a plan which

is seldom, if ever, used to actually program for a child or youth experiencing any type of disabling condition.

Individualized Education Program means a written plan for the education program of a child or youth with disabilities that has been developed by a school in accordance with rules adopted by the State and in provision with the reauthorization of the Education of the Handicapped Act (EHA) now termed: Individuals with Disabilities Act or IDEA. The program must consist of present level of performance which must lead to statement of need for specialized educational services which then generate goals and accompanying objectives. These education objectives must consist of three parts: the desired behavior to be changed, improved or decreased stated in specific observable and measurable language, the conditions under which that behavior is to occur and the criteria for acceptable performance. Education Objectives give rise to the discussion regarding the degree of success the child can be expected to attain in the general education setting with no additional assistance. From this point, the team makes programming decisions about the most appropriate, specific services and interventions which the individual will need in order to begin to meet success. Lastly, a placement decision is made regarding categorical programming. The IEP is a binding service agreement, not a contract of success.

Interagency - one or more agencies, programs, or systems collaborating toward mutually-beneficial results, common goals.

Inter-team - two or more teams collaborating toward mutually-beneficial results, common goals.

Intervention - an adaptations, accommodation, or support to teachers, service providers, families, individuals, communities, teams, or systems structured to assist the child/youth toward accomplishment.

Learn - an increase in one's cognitive repertoire.

Life Skills - those competencies necessary for the individual to function in the community of his/her choice.

Parent or Parenting Individual - primary caretaker and advocate for a child or youth.

Policy - the use of the legislative system to communicate and promote issues concerning deaf-blindness and the use of the legal system to enforce laws that affect individuals with deaf-blindness.

Success - positive results achieved and valued from the individual's perception and perspective.

Support Services - those services identified as appropriate to enhance independent living skills, employment skills, leisure/recreation, and community integration.

Team - a community of individuals working toward win/win results for a child/youth.

Training - the educational enhancement of an individual toward improved competency.

Values - the way things should be (as expected and viewed by the individual).

Whole Child Assessment - a systematic process to identify specific strengths and areas for intervention in academic skill development, social/emotional/affect behaviors and choices, potential vocational interests, functional skills for interdependent life choices, and the methods by which the child/youth processes information: modality and/or learning style and/or communication choices, listening, writing, and language usage.

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User Satisfaction Form

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User Satisfaction Form

We ask that you take some time to consider your responses to the *Guide to Services for Individuals with Deaf-Blindness* and how you have used it. Therefore, please do not complete this form until you have used it at least once and referred to it at least three times. Your responses will be carefully considered and will give direction to the Advisory Council in the consideration to revisions and additions.

Please return this form to:

Minnesota Deaf-Blind Project
Room 201
Capitol View Center
70 West County Road B2
Little Canada, MN 55117

Name_____

School District/Cooperative_____

Agency or Program_____

Address_____
_____
_____
_____

1. When did you receive the *Guide to Services for Individuals with Deaf-Blindness*?

2. Did you receive the *Guide to Services for Individuals with Deaf-Blindness* at a workshop, seminar, conference or public meeting? If so, please describe.

3. Why did you take the time to read this manual?

4. What did you find as most helpful about the guide?

5. Have you requested additional copies of this guide? Did you receive them? If yes, please indicate how many and for whom the request was made. (Service providers, families, individuals, etc.)

6. Has any portion of this guide been particularly difficult to understand or unusable for you? If yes, please identify which portion and explain briefly the confusion.

7. Have you shared any portion of this manual with students or other consumers? If yes, which portions and under what circumstances?

8. Have you shared any portions of this manual with parents and/or parenting individuals? If so, which portions and under what circumstances?

Thank you for your time and comments!

Order Form

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Guide to Services for Individuals with Deaf-Blindness
Order Form

Name:_____

Address:_____
_____
_____
_____

Organization:_____
_____
_____

Number of Copies:_____at $4.50 each = _____
+ $.50 postage and handling per copy; **total inclosed = _____**

Questions?
Call: 1-800-848-4905 (voice or TTY)
or, 612-779-5837

Please send remittance and order form to:

Minnesota Deaf-Blind Project
Room 201
Capitol View Center
70 West County Road B2
Little Canada, MN 55117

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An Activity of the Minnesota Deaf-Blind Technical/Assistance Project